

# SRI International

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**Kansas Early Intervention Longitudinal Study**

## **CHILDREN AND FAMILIES ENTERING EARLY INTERVENTION IN KANSAS**

**Final**

**SRI Project 10101**

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The Kansas Early Intervention Longitudinal Study (KEILS) is being conducted by SRI International under a contract (#99-156) between SRI International and the Kansas Department of Health and Environment. KEILS is a collaborative effort of SRI International and Research Triangle Institute.



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# **1. INTRODUCTION**

In 1986, federal legislation (P.L. 99-457) created the Early Intervention Program for Infants and Toddlers with Disabilities, now Part C of the Individuals with Disabilities Education Act, as amended in 1997 (IDEA97). Through this legislation, states have received funds to build coordinated, interagency systems of early intervention services. The years that followed have seen steady growth in the number of infants and toddlers served through Part C, increasing from an estimated 128,000 in 1988 (U.S. Department of Education, 1990) to 188,926 in 1998 (U.S. Department of Education, 2000). In order to meet the need for more and better information about Part C and its participant states, the Office of Special Education Programs (OSEP) of the U.S. Department of Education commissioned SRI International to conduct the National Early Intervention Longitudinal Study (NEILS). NEILS is following a nationally representative sample of children and families who were recruited into the study from September 1997 through November 1998 as they entered early intervention for the first time. Kansas was one of the 20 states included in the NEILS sample.

In December 1998, the Kansas Department of Health and Environment contracted with SRI International to collect data on an additional sample of children receiving early intervention services in Kansas. This supplemental sample, when combined with data from the Kansas sample included in NEILS, would allow estimates to be generated for the population of children in early intervention in the entire state. The study procedures that were followed were identical to those carried out for NEILS. The data collection for the supplemental sample involved interviews with families, service data forms from service providers, service provider surveys, and program director surveys. Years 1, 2, 3, and 4 of the Kansas Early Intervention Longitudinal Study (KEILS) correspond to calendar years 1999, 2000, 2001, and 2002.

KEILS will address the following study questions:

- a) Who are the children and families receiving early intervention services in Kansas?
- b) What early intervention services do participating children and families receive and how are they delivered?
- c) What outcomes do participating children and families experience?
- d) How do outcomes relate to variations in child and family characteristics, services provided, and costs?

A total of 316 families are included in KEILS. In addition to the 68 families recruited as part of the national study, an additional 248 families were recruited as the supplemental sample. For all of the analyses presented here, data from these two samples are combined.

## **Enrollment in the Study**

The data presented in this report are based on a statewide representative sample of families who entered early intervention in Kansas for the first time between April 15, 1997 and January 19, 2000. The families recruited as part of the national study had Individualized Family Service Plan (IFSP) dates ranging from 9/15/97 to 5/19/98. The additional families had IFSP dates ranging from 3/30/99 to 1/19/2000. The data were collected from early intervention programs in

74 counties in Kansas. Four counties were selected for the national study and an additional 70 were identified for the supplemental sample. Kansas is organized around networks for the provision of early intervention services. Some networks are made up of a single county while others are made up of multiple counties. When a county from a multiple county network was selected for the study, all of the other counties in the network were invited to participate, bringing the total to 74 counties.

The Kansas Department of Health and Environment contacted networks and enlisted their participation in the study. SRI mailed recruitment materials and forms to each of these networks. Each network was given a target number of children to recruit for the study based on the number of children they served annually in early intervention. The sum of the targets was 281 – the total number of additional children to be recruited.

Recruitment for the supplemental sample began in April 15, 1999. It had been scheduled to end in June 1999 but because sites had not yet reached the target number, recruitment was extended by several months. Recruitment ended on January 19, 2000. Although only 248 of the 281 children were recruited, it was decided to end recruitment because it had already extended far beyond the original end date and because the number of families recruited, although slightly less than ideal, was adequate to generate reliable statewide estimates.

As part of the process of enrolling children in the study and to provide a check on the representativeness of the sample of families who agreed to be in the study, basic demographic information was collected on all families who entered early intervention during the recruitment period. This information was collected on a one-page form that contained no personally identifiable information. Enrollment information was collected on 595 children.

Of the 595 families that completed enrollment forms, 501 were eligible for the study (i.e., had a child under 31 months of age and an adult in the household who spoke English or Spanish). Of the 501 eligible, 316 families agreed to participate in the study for an agreement rate of 63%. When a family agreed to be in the study, they provided their name, address, and phone number to the research team.

### **Data Collection: Family Interview**

Once a family was enrolled in the study, Research Triangle Institute (RTI), working under sub-contract to SRI, contacted the family for an interview with a family member familiar with the child and the child's services. These interviews could be completed up to four months from the date of the IFSP although most (67 %) were completed within the first two months. RTI was able to contact 305 families (97%) for this first interview. Most of the respondents were the child's biological mother (87%) and a few were the adoptive mother (3%).

### **Data Analysis**

The data in this report are based on information collected through the one-page enrollment form and the first family interview. All data are weighted, which means that numerical weights have been applied to the raw data. The procedures for calculating the weights are described in detail in Appendix A. Because of the nature of the sample selection procedures employed and the weights applied to the data, the percentages and means presented in this report represent

statewide estimates. For example, the reader should view the percentage of boys in early intervention presented in the next chapter as the best available estimate of the percentage of boys in early intervention in the state. It should not be read as the percentage of boys in the sample.

The percentages and means presented are only estimates of the actual percentages and means that would have been obtained if all children entering early intervention in the state had been included in the study. The estimates vary in how closely they approximate the true measures. To examine the precision of the estimate, researchers used a statistic called the “standard error”.

To determine the precision of a particular percentage or mean, the reader can construct a confidence interval for the estimate by multiplying the standard error by 1.96. The result is the range around the estimate within which the true measure would be found in 95 out of 100 samples. For example, as noted in the findings, 66.4 percent of children receiving early intervention in Kansas were male. The standard error of that estimate, 3.8, is multiplied by 1.96, letting us assume with 95% confidence that the true percentage of males falls within a range of  $\pm 7.45$  percentage points, or 58.95 to 73.85 percent. The standard errors associated with the data reported in the tables throughout the next section of this report (Findings) are contained in tables in the next section or in Appendix C.

## **Limitations**

One limitation of the study is the potential for bias due to incomplete data. Every effort was made by SRI to obtain enrollment information for every family that lived in the sample counties and enrolled in early intervention for the first time during the study recruitment period. However, one of the reasons for incomplete data was uneven adherence to study recruitment procedures by some enrolling programs. Despite the importance placed on completing the data form from all families, we have reason to believe that not all early intervention personnel completed forms for all families. SRI worked with the sites throughout the recruitment period to minimize these problems but we do suspect that there were some families for whom data forms were not completed. We have no particular reason to believe that families for whom we do have data differed in any systematic way from families for whom we did not have data. To the extent this is true, there should be no bias introduced by the incompleteness of the resulting information.

## 2. FINDINGS

### Overview

The findings are organized around four topics related to children, families and early intervention services. They are:

1. Characteristics of infants and toddlers entering early intervention in Kansas (demographic, health, developmental, and behavioral characteristics).
2. Characteristics of families of children entering early intervention in Kansas (family structure, education, employment, public assistance, and income characteristics).
3. Experiences of families entering early intervention
4. Child care and other services of children entering early intervention

In each section, the data are reported for the entire group of children and families. For key characteristics, we examined the data by a set of child and family background characteristics. These are: gender; race/ethnicity; age at first Individualized Family Service Plan (IFSP); inferred eligibility category (explained below); caregiver's education level; family income; and receipt of public assistance. Analyses not included in this chapter are presented in Appendix C.

### Characteristics of Infants and Toddlers Entering Early Intervention (EI) in Kansas

**Demographic and Background Characteristics.** Table 1 summarizes some key characteristics of infants and toddlers entering early intervention in Kansas for the first time. Two-thirds of the children (66%) were boys. Boys were also over-represented in the national population of infants and toddlers in early intervention (61%). The overrepresentation of boys in special needs populations has been noted among older children as well (U.S. Department of Education, 1998). Looking at minority status, we see that 23% of children entering early intervention in Kansas during the study period were from minority ethnic groups, compared to 47% nationally. Children were most likely to enter early intervention in Kansas when they were under 12 months or over 24 months (discussed in detail under "Reasons for eligibility"). One in 20 (5%) of children entering early intervention in Kansas was in foster care, which was slightly less than the figure for early intervention nationally (7 %).



**Table 1. Demographic Characteristics of Children Entering Early Intervention in Kansas**

Child demographic characteristics	Percent	SE	N
<b>Gender</b>			595
Male	66.4	3.8	
Female	33.6	3.8	
<b>Race/ethnicity</b>			591
White	77.1	5.2	
Minority	22.9	5.2	
<b>Child's age at entry into EI/initial IFSP</b>			595
Up to 6 months.	17.6	4.1	
6 months up to 12 months.	13.2	2.1	
1 year up to 18 months	9.9	1.4	
18 months up to 24 months	16.9	1.9	
2 years to 30 months.	27.7	3.4	
30 months up to 36 months	14.7	2.8	
<b>In foster care</b>			595
Yes	4.5	1.6	
No	95.5	1.7	

**Reasons for Eligibility.** The basic philosophical and empirical basis for early intervention is that providing appropriate services early has potentially greater impact than commencing services later. Therefore, an important policy goal is to identify and get children with developmental problems into programs as early as possible. The average age of the child at the time of referral was 17.6 months (See Table 2). Around 34% of children were under 12 months at the time of referral. Another 29% were between 12 and 24 months, and nearly 37% were 24 months or older at the time of referral. The average age of the child at the time the IFSP was developed was 19.1 months (See Table 2). This compares to an average of 17.1 months for the nation. Figure 1 shows the distribution of ages in months of children at the time of the IFSP in Kansas compared to the nation. Each bar shows the percentage of all entering who were a given age at entry. The graph shows clearly that more children are entering early intervention in Kansas in the first, and especially in the third year of life, than in the second. Around 31% of children began early intervention for the first time in Kansas between birth and 12 months. Another 27% began in their second year, and 42% in their third year. The age distribution at IFSP for Kansas differs somewhat from that for the rest of the nation. Nationally, 38% children began early intervention in the first year of life, 28% in the second, and 34% in the third.

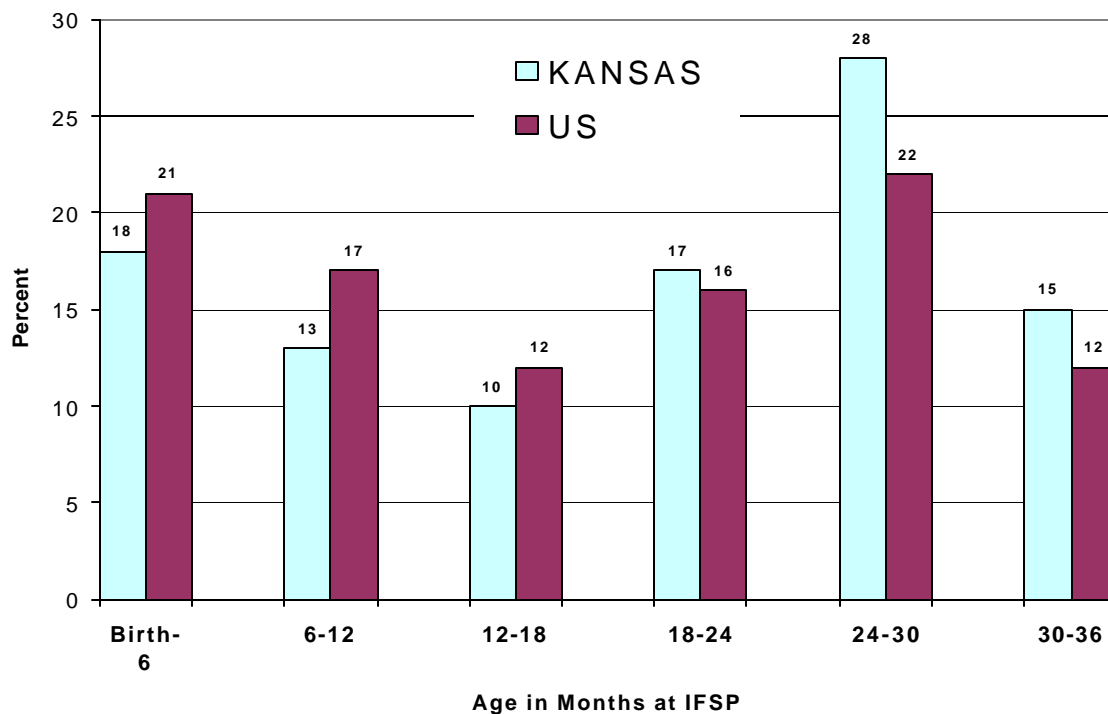
Federal law specifies the general eligibility criteria for receiving early intervention services. A child is to be provided early intervention services because she or he: 1) is experiencing developmental delays in one or more of the areas of communication development, physical development, social or emotional development, and adaptive development; or 2) has a diagnosed physical or mental condition that has a high probability of resulting in developmental delay. The law also gives states the option of serving children who are at risk for developmental delay (20 U.S.C § 1432, as amended by the Individuals with Disabilities Education Act of 1997). Kansas serves children experiencing developmental delays and those that have diagnosed conditions but

does not serve children who are at risk for developmental delay.

**Table 2. Age of Children Entering Early Intervention in Kansas**

		SE	N
<b>Age at referral to early intervention</b>			
Average months of age at referral	17.6	1.1	582
<b>Percentage whose age at referral was:</b>			
Less than 6 months	22.2	4.3	
6 months up to 12 months	12.1	1.3	
12 months up to 18 months	10.1	1.3	
18 months up to 24 months	18.7	2.1	
24 months up to 30 months	26.4	4.2	
30 months or older	10.5	2.6	
<b>Age at IFSP</b>			
Average months of age at IFSP	19.1	1.1	595
<b>Percentage whose age at IFSP was:</b>			
Up to 6 months	17.6	4.1	
6 months up to 12 months	13.2	2.1	
12 months up to 18 months	9.9	1.4	
18 months up to 24 months	16.9	1.9	
24 months up to 30 months	27.7	3.4	
30 months or older	14.7	2.8	

**Figure 1. Age of Children at IFSP (Kansas and National Figures)**



Local early intervention staff were asked to indicate which one of these (developmental delay, diagnosed condition, or at risk) was the reason the child was found to be eligible for early intervention. Local staff were also asked to specify the nature of the reasons that would make the child eligible. Staff provided descriptors such as “motor delay” or “intraventricular hemorrhage”. Each term was coded using a multi-level, multi-dimensional classification scheme developed by the research team as explained in Appendix B. The levels of the coding scheme are shown in Appendix B. Based on a review of the frequencies for each level, a summary set of frequencies that collapsed some of the less frequent categories at the highest level of the coding scheme and retained some of the more frequent conditions at the lower levels were developed. These findings are shown in Table 3.

**Table 3. Descriptions of Reasons for Receipt of Early Intervention**

Reasons for receipt of early intervention	Percent	SE
Delayed development	8.3	1.8
Physical growth abnormality	1.5	1.1
Sensory systems impairment	2.2	0.8
Vision impairment <sup>a</sup>	0.7	0.4
Hearing impairment <sup>a</sup>	1.1	0.6
Motor impairment or delay	14.9	2.9
Physiological or neurological system impairment	1.2	0.5
Intellectual/cognitive impairment or delay	11.4	4.9
Social/behavioral impairment or delay	5.1	2.3
Speech/communication impairment or delay	55.9	3.4
Delay in self-help skills	3.5	2.3
Congenital disorders	6.8	1.2
Down's syndrome <sup>a</sup>	2.3	0.9
Prenatal/Perinatal abnormalities	11.7	2.7
Low Birth Weight <sup>a</sup>	7.7	1.8
Prenatal Exposures <sup>a</sup>	0.5	0.2
Illness or chronic disease	3.6	2.5
Musculoskeletal disorders	2.3	0.7
Central Nervous System Disorders	2.9	1.1
Cerebral Palsy <sup>a</sup>	0.8	0.5
Receiving Medical Treatment, Disorder not Identified	2.7	1.4
Social environment risk factors <sup>b</sup>	3.4	1.4

NOTE: N =585. Children could be receiving early intervention for more than one reason.

a Indented categories are included in the superordinate category above them.

b Social environment risk factors can encompass factors connected with the child's environment which may include child neglect, abuse, malnutrition, parenting problems, parent psychopathology, parental substance use, etc. Children in Kansas would need to have an additional factor in the above list to be eligible for early intervention since Kansas does not serve children solely on the basis of environmental risk.

The most frequently reported reason for receipt of early intervention was a speech/communication impairment or delay. Providers indicated that 56% of the children were eligible for early intervention for problems related to speech or communication. Other frequently reported reasons for the receipt of early intervention included motor impairment or delay (15%), prenatal/perinatal problems (12%), and intellectual/cognitive delays (11%).

As mentioned earlier, the research team developed a coding scheme that classified each of the 305 descriptors as one of the eligibility categories in the federal law. (See Appendix B for details and the conditions included in each category). However, since Kansas does not serve children at risk for developmental delay, only two eligibility categories were used with the data in this report. Also to be more consistent with the state terminology, ‘diagnosed condition’ is referred to as ‘established risk for developmental delay.’ Thus, most of the children were eligible for early intervention because of a developmental delay (84%), and a lesser proportion had an established risk for developmental delay (16%) (See Table 4).

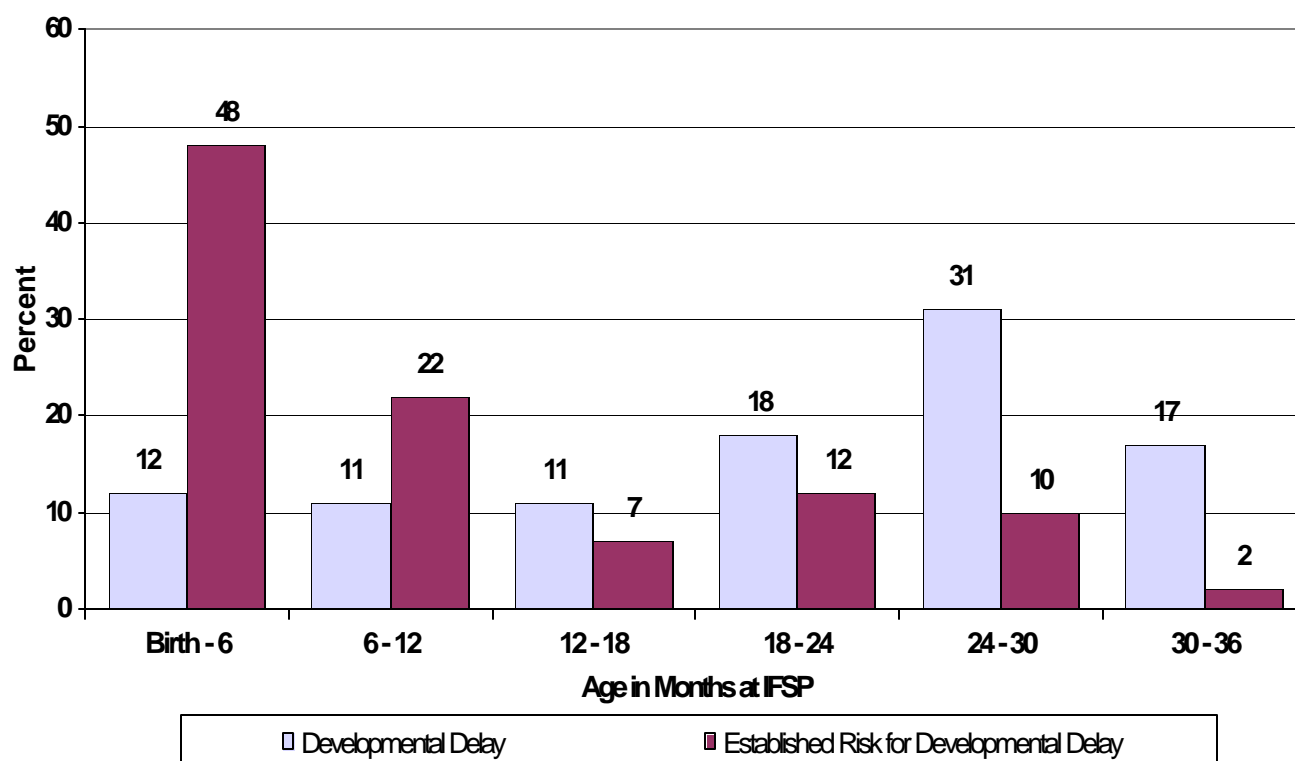
**Table 4. Eligibility Categories for Children Entering Early Intervention in Kansas**

Eligibility categories	Percent	SE
<b>Developmental Delay</b>	84.4	2.6
<b>Established Risk for Developmental Delay</b>	15.6	2.6

Note: N = 585

The age of the children at IFSP differed between the two eligibility groups (See Figure 2). For children eligible because of a developmental delay, 48% of the children were between 2 and 3 years old at the IFSP signing, while 70% of children eligible because of established risk for developmental delay had their IFSP signing in their first year ( $p<.01$ ). This is not surprising, since developmental delays can typically be diagnosed only when the children are old enough to be expected to have developed particular skills and have not yet done so. In contrast, some conditions that establish risk for developmental delay are evident at birth (e.g. Down syndrome, spina bifida, etc.).

**Figure 2. Age at IFSP by Reasons for Eligibility**



**Overall Child Functioning.** Parents were asked to report on their children's vision and hearing (See Table 5). Only 9% of the children receiving early intervention services were reported by parents to have a vision problem. Parents reported that 18% of the children receiving early intervention services had a hearing problem, compared to other children about the same age. This percentage is similar for boys and girls, and for children of different ethnic backgrounds. Socioeconomic indicators, such as family income and caregiver education, as well as age of entry into EI and reasons for eligibility were not related to whether or not a child had a vision or hearing problem.

**Table 5. Eyesight, Hearing, Use of Arms and Hands, Legs and Feet, and Use of Medical Devices in Children Entering EI in Kansas**

Child functioning characteristics	Percent	SE	N
<b>How is eyesight?</b>			294
Sees normally	90.8	2.1	
Vision problem	9.2	2.1	
<b>Child hearing compared with other kids</b>			299
Hears normally	81.5	3.7	
Hearing problem	18.5	3.7	
<b>How well does child use arms and hands?</b>			294
Uses both normally	80.9	2.7	
A little trouble	15.9	2.5	
A lot of trouble	2.9	1.2	
Not using one or both	0.2	0.2	
<b>How well does child use legs and feet?</b>			291
Uses both normally	81.0	2.6	
A little trouble	15.9	2.3	
A lot of trouble	2.5	1.0	
Not using one or both	0.6	0.5	
<b>Uses any kind of medical device?</b>			294
Yes	12.5	3.4	
No	87.5	3.4	

Parents were also asked to report on their children's use of arms and hands, legs and feet, and medical devices (such as an oxygen tank, catheter, or breathing monitor). About 19% of the parents described their children as having either a little trouble or a lot of trouble using their legs and feet, and 19% reported that their children have a little trouble or a lot of trouble using their arms and hands. Of the children that entered EI in their first year, more infants were reported as having trouble (a little or a lot) with their legs and feet (35%) compared with those who entered in their third year (6%) ( $p<.05$ ). Children entering EI in their first year also had more trouble (a little or a lot) with their arms and hands (39%) when compared to those children who entered EI in their third year (6%) ( $p<.01$ ). A little over 38% of children with an established risk for developmental delay had more trouble (a little or a lot) with their arms and hands compared to 15% of children with developmental delays ( $p<.05$ ). None of the other child and family demographic characteristics were associated with children's use of their arms and hands, or their legs and feet. A few children

were reported to use some kind of medical device (13%). Use of a medical device was not related to gender or ethnic background. Age at entry into EI was related to the likelihood of using a medical devices: children who began early intervention in the first year were 15 times more likely (30%) to use a medical device than were children who entered after 24 months of age (2%) ( $p<.01$ ). Caregiver education was also related to use of a medical device. Infants whose caregivers had less than a high school degree were nearly 5 times more likely (19%) to use a medical device than children whose caregivers had a bachelor's degree or higher (4%) ( $p<.05$ ).

Parents were also asked questions on the child's communication abilities, i.e., how well the child makes his or her needs known to others, the way in which these needs are communicated to the family and others, and how easy it is to understand the child compared to children of the same age (See Table 6). Parents reported that nearly half (49%) the children had a little trouble communicating, while nearly 1 in 4 children (24%) had a lot of trouble communicating. Parents reported more than half the children as being somewhat hard to understand, while 1 in 4 (25%) were reported as being very hard to understand. Families reported that the three most common ways by which children made their needs known were gestures, sounds (not words), and words. None of the child and family demographic characteristics were associated with the way in which the children communicated their needs. More than half the children who entered EI at 12 months or younger (55%) were reported as making their needs known well when compared to only 21% of the children who began EI at 24 months or older ( $p<.01$ ), suggesting that many of those who entered early intervention as toddlers had communication problems.

**Table 6. Communication of Children Entering Early Intervention in Kansas**

Communication characteristics	Percent	SE	N
<b>How well does child make needs known?</b>			190
Communicates well	23.7	4.5	
A little trouble	48.7	6.6	
A lot of trouble	23.9	4.1	
Doesn't communicate	3.6	2.7	
<b>Others understanding of child's speech</b>			84
Very easy	7.2	5.9	
Fairly easy	13.9	3.7	
Somewhat hard	53.5	8.1	
Very hard	25.3	6.7	
<b>How does child make needs known?</b>			190
Words	41.7	5.0	
Sounds (not words)	70.0	6.6	
Gestures	79.9	4.9	
Sign language	5.4	2.2	
Communication board/book	0.5	0.6	
Computer/electronic item	0.0	0.0	
Crying	17.7	4.3	
Leading, take by hand	0.0	0.0	
Aggression, hitting	0.0	0.0	
No communication at all	0.0	0.0	

In general, children entering EI at less than 12 months were more likely to have trouble in motor functioning than children entering after 12 months. Overall, a majority of children entering EI in Kansas had trouble communicating their needs to family and others, and were reported as being somewhat to very hard to understand. Furthermore, many of those children that entered EI as toddlers had communication problems.

## Health Characteristics

**Birth Experiences.** A sizeable percentage of infants and toddlers in early intervention in Kansas had birth histories that were compromised (See Table 7). Approximately 24% of children in early intervention in Kansas were born at low birth weights (LBW, <2500 grams). Furthermore, 7% had birth weights of less than 1000 grams, which is considered to be very low. Nearly 24 % of children in early intervention were born prematurely (<37 weeks gestation). Thirty-six percent spent extra nights in the hospital after birth, and 32% were in Neonatal Intensive Care Units (NICU) after birth. Girls in early intervention were a little more likely to be LBW than boys; 30% of the girls entering EI in Kansas had birth weights of less than 2500g, compared to 20% of boys ( $p<.05$ ). Ethnicity was also associated with birth weight for children in early intervention. More than half (52%) of minority infants in early intervention were LBW, whereas only 17% of White children in early intervention were LBW ( $p<.01$ ). Not surprisingly, infants entering early intervention at younger ages were more likely to be low birth weight: 42% of the infants that entered early intervention in their first year were LBW, whereas only 9% of those entering early intervention after age 2 were LBW ( $p<.05$ ). Socioeconomic status was associated with birth weight. Among families who earned less than \$15,000 a year, nearly 38% of the children were LBW compared to 19% for families making \$75,000 or more a year ( $p<.01$ ).

Gestational age showed a similar relationship to that seen for birth weight. Thirty-two percent of the children of families with annual income less than \$15,000 were pre-term. On the other hand, only 15% of infants from high-SES families (annual income over \$75,000) were pre-term ( $p<.01$ ). Furthermore, of the infants whose caregivers had less than a high school degree, nearly 32% were pre-term compared to 15% for the children of those with a bachelor's degree ( $p<.01$ ). Furthermore, nearly 47% of children entering EI in their first year were pre-term compared to only 10% of those entering after age 2 ( $p<.01$ ).

Another marker of birth experience is whether or not the infant was in a neonatal intensive care unit (NICU) after birth. About one-third of children (32%) entering EI had been in a NICU. Not surprisingly, there were differences among those in the two eligibility categories with regard to a previous stay in the NICU. Of those children who were eligible for early intervention based on an established risk for developmental delay, more than half (51%) had experienced NICU care after birth, while the comparable figure for those with developmental delays was 27% ( $p<.01$ ). Of the minority infants, nearly 48% had been in a NICU compared to only 28% for White infants ( $p<.05$ ). More than half (65%) the infants who entered EI in their first year had previously been in a NICU, compared to only 12% for those who entered after 24 months of age ( $p<.01$ ).

**Table 7. Birth Characteristics of Children Entering Early Intervention in Kansas**

Birth characteristics	Percent	SE	N
<b>Birth weight</b>			288
999 grams or less	6.6	3.2	
1000 to 1499 grams	6.0	2.4	
1500 to 2499 grams	10.6	2.4	
2500 grams or more	76.8	4.8	
<b>Gestational age</b>			288
24 weeks or less	1.2	0.5	
25 to 28 weeks	6.7	2.9	
29 to 32 weeks	6.6	2.0	
33 to 36 weeks	9.3	1.9	
37 weeks or more	76.3	4.1	
<b>Nights in hospital</b>			293
None	63.9	5.8	
1-4 days	5.1	1.6	
5-14 days	9.4	1.9	
15-30 days	7.7	2.5	
31-61 days	7.8	2.3	
62-91 days	4.2	1.3	
92-121 days	0.7	0.6	
More than 121 days	1.2	0.7	
<b>NICU hospitalization after birth</b>			292
Yes	31.6	6.6	
No	68.4	6.6	

About one-third (36%) of infants entering EI had spent one or more extra nights in the hospital after birth. A larger percentage of girls spent extra nights in the hospital after birth (45%), relative to boys (30%)( $p<.01$ ). It was also interesting to note that among infants who began EI in their first year, a majority (70%) spent nights at the hospital after birth in contrast to only 15% of children who began EI in their third year ( $p<.01$ ). Also, of those infants who were eligible for EI based on an established risk for developmental delay, more than half (54%) spent extra nights in the hospital compared to 32% who were diagnosed as having developmental delay ( $p<.05$ ). Furthermore, 46% of infants whose caregivers had less than a high-school degree spent extra nights in the hospital versus 27% that had a college degree or higher ( $p<.01$ ). Finally, 48% of infants whose household income was very low (less than \$15,000) spent extra nights at the hospital compared to only 24% who had household incomes of \$75,000 or higher ( $p<.01$ ).

These findings indicate that many infants and toddlers in early intervention in Kansas had compromised birth histories. This was especially true for minority children, children from low-income families, and children with less educated caregivers. Children with compromised birth histories were more likely to be eligible for early intervention because of an established risk for developmental delay. They were also more likely to enter early intervention at younger ages than children who had no difficulty at birth.



**Health Status.** A large proportion of parents rated the overall current health status of their children in early intervention as good, very good, or excellent (89%). Health status was not differentially associated with the child's gender, ethnicity, or age of entry into EI. Health status was, however, associated with family income. Only 25% of infants whose families were in the lowest income bracket received an "excellent" health rating, as compared to 48% of those infants in families in the highest income bracket (over \$75,000) ( $p < .01$ ). Surprisingly, there were no associations between reasons for eligibility and current health status.

More than 6 in 10 (61%) of the children had not been hospitalized again after coming home from the hospital at birth. Of the group that was, 32% were hospitalized between 1 to 14 days, with only 4% being hospitalized for 15-61 days, and only 3% for more than 61 days since birth. Nights of hospitalization after returning home from the hospital was not associated with gender, ethnicity, inferred reason for eligibility, and receipt of welfare and food stamps. However, of those children who entered EI in their first year and second year, nearly half were hospitalized at some point after coming home from the hospital while only 23% of children who entered EI in their third year were hospitalized after returning from the hospital ( $p < .01$ ).

Nearly all the children (97%) were reported as having a place they where their medical history was known and they could get regular medical care; but this was not related to any of the child or family demographic variables. One in every five children receiving early intervention services (20%) in Kansas was taking some kind of prescription medication regularly. Gender and ethnicity were not related to the child's taking of medication. As has been seen with several indicators, the children entering early intervention at younger ages were more medically involved than children entering at later ages. This same finding holds for use of medication. Children entering EI in Kansas in their first year were ten times more likely (41%) to use regular medications than children entering after 24 months (4%) ( $p < .01$ ). Furthermore, children from the lowest income families (30%) were more likely to be taking medications than those from the highest income bracket (4%) ( $p < .01$ ).

In terms of health insurance coverage, nearly all families (94%) were covered by health insurance. However, there was an association between caregiver education and health insurance coverage. All families with caregivers with a bachelor's degree or higher were covered by health insurance, while only 86% of those families with caregivers with less than a high school diploma were covered by health insurance ( $p < .05$ ).

With regard to type of health insurance, 66% of the families reported that their child was covered by health insurance from an employer or union or coverage that the family bought directly; 37% reported that the child was covered by government-assisted health insurance (e.g. Medicaid); and 5% reported being covered by some other health insurance program. Nearly 1 in 4 families (24%) reported being covered by a Health Maintenance Organization (HMO). Most of the families (98%) reported they had not needed to change insurance plans or buy extra insurance for their children because of a child's special needs. Only 17% of the families reported that they tried to get their insurance or health plan to pay for something for the child, but the plan would not pay. Of the services that the insurance plans would not pay for, 47% were reported as being therapy services.

Among White families, nearly 72% reported having health insurance from an employer or union, or one that the family buys directly, compared to 42% for minority families. Nearly 96% of caregivers with a college degree or higher reported having such insurance, while only 43% of caregivers with lower education (less than a high school degree) reported having such insurance coverage for their children ( $p<.01$ ). Most families (80%) with annual household income of \$15,000 or less reported not having such insurance for their children. In comparison, all of the families with annual incomes of \$75,000 or more reported having health insurance from an employer or union, or one that the family bought directly ( $p<.01$ ).

In summary, most children in Kansas were healthy at the time they began EI. Certain demographic factors were found to be associated with health status, including family income. Consistent with other findings, the data for use of medication indicated that children who began early intervention services at younger ages were more medically involved than those who began later. Families with less educated caregivers were less likely to be covered by health insurance. Similarly, a larger proportion of low-income families report not being covered by health insurance (from an employer or union, or one that family buys directly) when compared to higher-income families.

## **Development and Behavioral Characteristics**

**Developmental Milestones.** To examine developmental progress, the research team identified key milestones for five developmental areas: social, cognitive, motor, language, and self-help. For each milestone, parents were asked to report whether the child “doesn’t do it at all yet, does it but not well, or does it well.” The selection and development of the milestone items reflected achievements that are universal to children based on documentation in existing literature regarding representative ages of achievement. Pilot testing determined that the selected items could be reported by parents.

This report presents how parents in Kansas rated their children's attainment of key developmental milestones at the time they entered early intervention. Later reports will examine changes in these developmental areas. Milestone data are reported for three ages groups: children who were less than 12 months at the time of the interview, 12 to 24 months, and greater than 24 months of age. As expected, there was a strong relationship between age and the percentage of children who can perform a given milestone. Table 8 presents the percentage of parents of children in each age group who reported the child could do the milestone well. Also provided for each milestone is the age when approximately 90% of the general population can perform this milestone. Together these data provide a rich descriptive picture of the capabilities and needs of children as they enter early intervention in Kansas. The reader is reminded that these three groups of children differ in other important ways in addition to age. The youngest children were more likely to be eligible for early intervention because of an established risk for developmental delay, more likely to have been low birth weight, and more medically involved.

With regard to mobility, most but not all children in early intervention who were 24 months of age or younger could crawl or sit alone. Even though 90% of the general population attains these milestones at 11 months or earlier, within early intervention, 9% of children 12 to 24 months were not yet crawling and 3% of children in this age group could not sit unassisted. Walking without holding on to anything, the ultimate mobility attainment of toddlerhood, was

done well by 69% of those in the 12 to 24 month age group and 98% of those in the group over 24 months ( $p < .01$ ).

**Table 8. Developmental Milestone Attainment by Children Entering Early Intervention in Kansas**

Developmental milestones <sup>a</sup>	Age Group in Months at Interview		
	<12	12-24	>24
<b>Mobility</b>			
Crawls, scoots, creeps (11)	32.0	90.8	100.0
Sits alone (11)	28.6	97.1	100.0
Walks without holding on to anything (17)	<1	68.6	97.5
<b>Hand Use</b>			
Grasps and releases (10)	62.9	98.4	100.0
Picks up small things (12)	21.0	87.6	96.6
<b>Communication</b>			
Brightens, smiles to own name (7)	74.9	100.0	100.0
Gestures to communicate (12)	29.8	81.9	98.9
Says mama or dada (12)	11.2	50.5	89.1
Responds to simple verbal request (13)	4.4	42.4	86.9
Says at least 20 different words (17)	--	7.1	41.4
Repeat or imitate a word someone says (18)	4.2	17.3	39.9
Says at least 2 or 3 words together in a sentence (25)	--	5.7	30.3
<b>Independence</b>			
Eats bite size food with fingers (11)	12.9	93.9	99.5
Holds cup to drink (18)	10.2	81.2	96.3
Takes off socks without help (23)		68.3	84.8
<b>Object Play</b>			
Explores/manipulates objects (11)	44.2	100.0	99.5
Puts things into and out of things (12)	16.9	83.6	97.1
<b>Social Play</b>			
Responds to peek-a-boo game (8)	65.9	99.5	100.0
Greets people with a wave, smile, or hi (24)	51.2	80.3	96.9

<sup>a</sup> NOTE: Numbers in parentheses indicate the age in months at which approximately 90% of all children in the general population have achieved this skill

The two milestones related to hand use show the same pattern: more children attain success at older ages, but some children also lag behind. Eighty-eight percent of children 12-24 months and 97% of the older group were able to pick up small things. Since nearly all children in the general population have attained this skill by 12 months, these data reflect a small percentage of children in the early intervention population with fine motor difficulties.

The milestone data on communication reinforce the earlier findings about the predominance of communication problems within the population of children in early intervention in Kansas. In general, the children were relatively skilled with regard to responding to their names and communicating with gestures, but less so with regard to word usage and vocabulary. Whereas most children say “mama” or “dada” by 12 months of age, only 51% of those 12 to 24 months of age when entering early intervention had attained this skill. Even among those over 24 months, only 89% said “mama” or “dada.” The other communication milestones present a similar picture. Almost all children say at least 20 different words by 17 months. Among those entering early intervention who were older than 24 months, only 41% could say at least 20 different words.

Upon entry to early intervention, the older children were relatively successful with regard to independence. Most of the 12 to 24 month olds (94%) could eat bite size food with their fingers, as could all of those over 24 months. Most of the children in each of these groups could also hold a cup to drink (81% and 96%, respectively). Taking off socks was more difficult, but this is a skill not usually mastered until 23 months of age. Eighty-five percent of the children over 24 months could take their socks off without help.

The children entering early intervention were also relatively successful in the areas of manipulating objects and social play although as in all areas, some children were experiencing difficulty. For example, putting things in and out of things is normally mastered by 12 months. Among those 12 to 24 months old at entry to early intervention, 84% could do this activity well. Among those older than 24 months, the figure had risen to 97% (meaning, however, that 3% of the oldest children were not able to put things in and out of things).

Overall, the results on attainment of developmental milestones among children entering early intervention in the Kansas population indicate small percentages of children had difficulty in each of the developmental areas (not necessarily the same children) as evidenced by delayed attainment of age-appropriate skills. The notable exception was in the area of communication, where the percentages of children with delayed attainment were far greater than in the other domains. As seen in previously presented data, this further reinforces the finding that infants and toddlers in Kansas experience a variety of different developmental problems but many of them have communication problems.

**Engagement Behavior.** Parents were also asked to characterize a number of different aspects of their child’s behavior, including how the child interacts with the environment and with other children and adults. These differ from the milestones in that many of these aspects do not have a predictable developmental trajectory (notwithstanding that almost all behavior will change as children grow older). They are highlighted in Table 9. Items that were included addressed a variety of behavioral attributes, including involvement, persistence, social engagement, activity level, distractibility, threshold to respond, and attention. For many of these items, parents were read a description and asked how much it was like their child. Parents responded by indicating this was not like their child, a little like their child or very much like their child. Many of the items were not asked of parents of children younger than 12 months of age.

**Table 9. Engagement Characteristics of Children Entering EI in Kansas**

Engagement characteristic	Percent	SE	N
<b>Is child quiet and passive?</b>			292
Very much like child	13.6	4.3	
A little like child	23.4	4.3	
Not like child	63.0	4.6	
<b>Is child jumpy and easily startled?</b>			294
Very much like child	17.6	4.5	
A little like child	35.7	4.6	
Not like child	46.7	6.9	
<b>Does child pay attention and stay focused?</b>			291
Very much like child	40.2	4.5	
A little like child	38.7	3.3	
Not like child	21.1	3.7	
<b>Does child do things on his/her own even if hard?</b>			191
Very much like child	58.9	4.6	
A little like child	29.2	4.5	
Not like child	11.9	3.9	
<b>Does child try to finish things?</b>			186
Very much like child	18.7	5.2	
A little like child	38.6	4.9	
Not like child	42.8	5.3	
<b>Is child very active and excitable?</b>			191
Very much like child	45.7	6.7	
A little like child	26.2	5.8	
Not like child	28.1	4.4	
<b>Is child easily involved in everyday things?</b>			291
Very much like child	52.2	4.1	
A little like child	29.9	3.8	
Not like child	17.9	3.8	
<b>Is child distracted by sights and sounds?</b>			191
Very much like child	19.4	4.5	
A little like child	39.1	5.5	
Not like child	41.5	7.1	
<b>Child shows interest in nearby adults</b>			293
Very much like child	50.5	3.9	
A little like child	30.7	3.4	
Not like child	18.7	3.5	
<b>Child plays with other children</b>			190
No trouble	51.6	6.6	
Some trouble	38.0	5.7	
A lot of trouble	7.6	3.5	
Not around children	2.8	2.1	

**Table 9. Engagement Characteristics of Children Entering EI in Kansas (Concluded)**

Engagement characteristic	Percent	SE	N
<b>How aggressive is child with other children?</b>			190
Not at all	38.2	5.6	
Sometimes	53.4	4.8	
Often	8.4	3.5	
<b>How easy to soothe/manage is child?</b>			294
Easy	48.0	4.9	
Sometimes hard	38.6	3.9	
Often hard	13.4	3.8	
<b>How often does child have temper tantrums?</b>			191
Rarely or never	17.8	3.5	
Sometimes	57.4	6.7	
Often	24.8	6.2	
<b>How often does child have sleep trouble?</b>			292
Rarely or never	59.0	4.1	
Sometimes	23.9	2.5	
Often	17.2	3.7	
<b>How easy is it to take child to store or appointment?</b>			300
Easier than other children	25.0	3.9	
Just as easy	44.2	4.6	
A little harder	20.9	4.1	
Much harder	9.9	3.7	
<b>How easy to get a babysitter?</b>			289
Very easy	47.2	4.2	
Fairly easy	19.6	3.7	
Somewhat hard	14.9	3.6	
Very hard	18.4	5.5	

Most children (63%) in early intervention were described as not quiet or passive. About half (47%) were described as not jumpy or easily startled. Many parents reported that paying attention and staying focused was very much like their child (40%), or a little like their child (39%), although one in five said this was not at all like their child. Many parents saw their child as excitable and active; 46% said this was very much like their child. Similarly, 19% said being distracted by sights and sounds was very much like their child and another 39% said this was a little like their child. Most parents (59%) reported their child did things on his or her own even if hard. On the other hand, parents did not see their children as trying to finish things; only 19% said this is very much like my child. Children were generally characterized as easily involved in everyday things (52% very much like my child). Most children were seen as interested in nearby adults (51% very much, 31% a little).

About half the children (52%) were seen by their parents as having no trouble playing with other children, with 38% having some trouble. About half (53%) were seen as sometimes aggressive, with another 8% seen as often aggressive. About half the children (48%) were seen as easy to soothe with 13% seen as often hard to soothe. Parents of one-fourth of the children reported they often had temper tantrums. At the other end of the spectrum, 18% reported their

child never had temper tantrums. Sleep problems were relatively rare; only 17% of children in early intervention were described as often having sleep problems.

There were some interesting differences in how children with different characteristics and family demographics were seen by their parents. Children that were under 12 months at the time of the interview were most likely to: be jumpy and easily startled; pay attention and stay focused; get easily involved in everyday things; and show an interest in adults.

Caregiver education was related to many of the child characteristics. Mothers with less than a high school degree either had children who were truly different or these mothers tended to see their children differently than mothers with more education. Children of mothers with less than a high school education reported their children were more likely to not pay attention and stay focused, were more active and excitable, far less likely to be easily involved in everyday things, and harder to soothe. Children of mothers with only a high school diploma were more likely to: get easily startled, finish things, and be distracted by sights and sounds.

Household income was also related to many of the child characteristics. Families that had household incomes below \$15,000 a year were more likely to report that children were easily startled, distracted by sights and sounds, had temper tantrums, and showed interest in adults nearby. Those families with a slightly higher annual household income (\$15,000-\$25,000) reported that their children were less likely to pay attention, to be involved in everyday things, and had some trouble playing with other children.

Two questions that were asked related to the child and family's interaction with those outside the family. Parents were asked how hard it is to take their child with them to the store or an appointment. Parents gave a variety of responses. One-fourth said their child was easier than other children to take places, 44% just as easy, 21% a little harder and 10% much harder. Interestingly, the perceived challenges posed in taking the child places was not related to child characteristics but to family characteristics. Children of mothers with less than a high school education were most likely to be seen as much harder to take places, as were children of families making between \$15,000 and 25,000 per year.

The second question related to interaction with persons outside the family was how easy it was for the family member to get a babysitter for the child. There are, of course, many reasons why a family could or could not get a babysitter that have nothing to do with the nature of the child's developmental delay or disability. Two-thirds (67%) of families said it was very easy or fairly easy to get a babysitter, with the remainder saying it was hard. The ease of finding a babysitter was not associated with any of the child and family characteristics.

## **Characteristics of Families Entering Early Intervention in Kansas**

**Family Demographics.** The family demographic characteristics (shown in Table 10) of children entering early intervention in Kansas were interesting. Many caregivers of children entering early intervention in Kansas had at least some college experience or a college degree. There was a fraction (1 in 5) of families that were very poor, i.e. had annual household incomes of less than \$15,000. A little over 2 in 10 (23%) were on public assistance. A majority of families had approximately four or more persons residing in the household when the child entered EI, and more than three-quarters of families had at least two adults living in the

household. Nearly 80% had between one and three children living in the household. Nearly a third of the caregivers were under 25 at the time of the child's birth. More caregivers were unemployed (58%) than were employed. Of those who were working, about half (49%) were employed full-time. Nearly three quarters (73%) of the caregivers were married, with most (92%) of their partners being employed, and 96% of the ir partners working full-time. Approximately 7 in 10 partners had some college experience, with a third (33%) having a bachelor's degree or higher. Finally, more than 8 in 10 (82%) of the partners were over 25 at the time of the birth of their child.

**Table 10. Characteristics of Families of Children Entering Early Intervention in Kansas**

Family demographic characteristics	Percent	SE	N
<b>Caregiver's education</b>			293
Less than high school diploma	10.0	3.7	
High school diploma or GED	30.5	5.6	
Some college	35.0	4.9	
Bachelor's degree or higher	24.5	8.6	
<b>Family income</b>			273
\$15,000 or less	20.2	5.2	
\$15,001-\$25,000	13.9	3.5	
\$25,001-\$50,000	33.4	4.6	
\$50,001-\$75,000	18.4	4.7	
Over \$75,000	14.1	5.8	
<b>Receipt of public assistance</b>			298
Yes	22.7	6.3	
No	77.3	6.3	
<b>Household size</b>			299
One	0.2	0.0	
Two	5.1	0.2	
Three	18.8	2.2	
Four	33.4	2.6	
Five	20.8	3.2	
Six	15.2	2.7	
Seven	6.5	2.3	
<b>Number of adults living in household</b>			299
One	13.5	4.2	
Two	77.6	5.5	
Three	7.5	1.9	
Four	1.5	1.0	
<b>Number of children living in household</b>			299
None	0.5	3.2	
One	23.0	2.4	
Two	33.2	2.7	
Three	23.9	2.9	
Four	13.3	2.5	
Five or more	6.1	0.6	



**Table 10. Characteristics of Families of Children Entering Early Intervention in Kansas  
(Concluded)**

Family demographic characteristics	Percent	SE	N
<b>Caregiver's age (at time of birth of child)</b>			290
13 to 17	1.9	1.1	
18 to 24	29.2	6.8	
25 to 30	30.9	4.4	
31 to 40	33.1	8.2	
41 to 50	5.0	1.7	
<b>Caregiver's employment</b>			288
Yes	41.8	3.6	
No	58.3	3.6	
<b>Caregiver's average weekly hours of employment</b>			129
Less than 20 hours	15.1	4.6	
20 to 35 hours	35.8	5.1	
More than 35 hours	49.1	5.3	
<b>Caregiver: marital status</b>			292
Married	72.6	6.9	
Unmarried Partner	8.2	2.5	
No spouse/partner in household	19.2	5.7	
Partner (unclear if married)	0.1	0.1	
<b>Partner: Employment</b>			232
Yes	92.4	3.3	
No	7.6	3.3	
<b>Partner's average weekly hours of employment</b>			211
Less than 20 hours	0.3	0.4	
20 to 35 hours	3.3	1.4	
More than 35 hours	96.3	1.6	
<b>Partner's education</b>			237
Less than high school degree	11.2	3.9	
GED or high school degree	20.4	4.6	
Some college	35.0	5.5	
Bachelor's degree or higher	33.4	9.5	
<b>Partner's age (at time of birth of child)</b>			236
13 to 17	0.9	0.6	
18 to 24	15.6	4.9	
25 to 30	27.9	4.6	
31 to 40	44.0	7.6	
41 to 50	10.5	3.2	

**Parenting, Community Participation and Life Situation.** Families were asked several questions about parenting issues, the kinds of support available to them, and how they feel about their current life situation. All three are being tracked as potential areas in which early intervention might change how families see themselves.

Families were presented with a series of statements and asked the extent to which they agreed or disagreed with each statement. How families responded is presented in Table 11. Almost all families either strongly agreed or agreed with most of the positively oriented statements, but there were some differences across the statements in percentage of families who strongly agreed. Whereas 82% of the families strongly agreed that they know how to care for the child's basic needs, only 54% strongly agreed that they knew how to help their child learn and develop. The behavior of a child entering early intervention was identified as a challenge by many families. Nearly 35% of families strongly agreed or agreed that they often had difficulty figuring out what to do about the child's behavior. Fifty-seven percent strongly agreed and 40% agreed that they knew how to work with professionals and advocate for their child's special needs. Almost all families thought that their children's ability to work and play together was pretty normal, even though they had a child with special needs; 51% strongly agreed and another 42% agreed. Most families had general sources of support in the community; 57% strongly agreed and 33% agreed that they have relatives or friends to turn to for help or support when they need it. Fewer families had support related to the child's special needs; only 72% agreed or strongly agreed that they had friends or relatives to help deal with the child's special needs. Lastly, most but not all families are able to participate in community activities. Only 28% percent of the families agreed or strongly agreed that they had little chance to take part in community activities like religious, school, or social events.

Families' perceptions on the parenting issues were related to household income and level of caregiver education. Compared to families with annual incomes over \$75,000, relatively low-income families (household income between \$15,000 and \$25,000) were less likely to report that they knew: how to take care of the child's basic needs; how to help children learn and develop; and how to work with professionals and advocate for what the child needs. Similarly, more than half the caregivers (54%) with less than a high school diploma reported that they had difficulty figuring out what to do about their child's behavior, compared to about 2 in 10 caregivers (20 %) with a college degree or higher ( $p<.05$ ).

Not surprisingly, caregivers with toddlers were more likely to report difficulty with the child's behavior. Almost half the caregivers with toddlers (children in their second year) at the time of IFSP (49%) reported having difficulty figuring out what to do about their child's behavior compared to only 21% of the caregivers with children who were under 12 months at IFSP ( $p<.05$ ). Furthermore, younger children seemed to have less impact on family routines. Over 6 in 10 families whose children were under 1 at IFSP (65 %) strongly agreed that their ability to play together as a family was pretty normal, compared to only 4 in 10 families (43 %) with children over 2 years of age ( $p<.05$ ).

**Table 11. Parenting and Community Participation**

Parenting and community participation by families	Percent	SE	N
<b>Know how to care for child's basic needs</b>			300
Strongly agree	82.4	4.0	
Agree	17.4	4.0	
Disagree	0	0	
Strongly disagree	0.3	0.4	
<b>Know how to help child learn and develop</b>			299
Strongly agree	54.1	3.9	
Agree	41.7	3.3	
Disagree	3.7	1.7	
Strongly disagree	0.4	0.5	
<b>Difficulties deciding what to do about child's behavior</b>			300
Strongly agree	7.9	3.9	
Agree	27.4	5.7	
Disagree	36.3	4.1	
Strongly disagree	28.4	3.6	
<b>Know how to work with professionals &amp; advocate child's needs</b>			300
Strongly agree	56.8	3.8	
Agree	40.4	4.2	
Disagree	2.6	2.4	
Strongly disagree	0.3	0.3	
<b>Ability to work and play together is pretty normal</b>			300
Strongly agree	51.2	5.5	
Agree	41.6	5.0	
Disagree	6.8	3.9	
Strongly disagree	0.5	0.3	
<b>Have relatives to turn to for help/support</b>			299
Strongly agree	56.7	5.7	
Agree	33.3	5.1	
Disagree	7.8	2.7	
Strongly disagree	2.3	1.0	
<b>Have relative/friends/others to help me deal with challenges I faced to do child's special needs</b>			298
Strongly agree	37.7	3.4	
Agree	44.6	3.8	
Disagree	15.2	3.2	
Strongly disagree	2.5	1.3	
<b>Have little chance for community activities</b>			295
Strongly agree	8.5	2.4	
Agree	20.1	3.6	
Disagree	42.1	3.4	
Strongly disagree	29.4	3.8	

Families also were asked a series of questions about their current and future life situation. These findings are summarized in Table 12. With regard to families' current life situation, two-thirds saw it as "excellent" (34%) or "very good" (31%). Upper-income families were more pleased with their current life situation. More than half (54%) the families with annual household incomes above \$75,000 reported an excellent current overall life situation for their family, compared to 23% of families with household incomes of less than \$15,000 ( $p < .01$ ).

**Table 12. Life Situation of Children and Families**

Life situations of children and families	Percent	SE	N
<b>Family's current overall situation</b>			299
Excellent	34.3	5.7	
Very good	31.4	3.8	
Good	24.9	5.3	
Fair	7.3	2.7	
Poor	2.1	1.9	
<b>Child's current overall situation</b>			299
Excellent	33.3	4.8	
Very good	37.4	4.6	
Good	23.7	2.6	
Fair	4.0	1.5	
Poor	1.5	1.8	
<b>Family's overall situation in future</b>			297
Excellent	48.9	5.2	
Very good	33.0	4.3	
Good	17.4	4.8	
Fair	.4	.3	
Poor	.3	.5	
<b>Child's overall situation in future</b>			299
Excellent	53.6	4.7	
Very good	31.9	3.8	
Good	12.3	3.9	
Fair	1.7	1.1	
Poor	.6	.7	

When asked about their child's current overall situation currently, 33% described it as "excellent", 37% described it as "very good", and 24% as "good." Families with more educated caregivers and with more income were more positive about their child's current life situation. Nearly half (49%) the families with caregivers with a college degree reported the child's situation as excellent, compared to only 17% of those with less than a high school diploma ( $p < .01$ ). Similarly 52% of families with household incomes above \$75,000 reported that their child's overall life situation was "excellent" compared to only 26% of low-income families (less than \$15,000 household income) ( $p < .01$ ).

Families were also asked their feelings about the family's and the child's future life situation. Looking towards the future, most families expected that their overall life situation would be

“excellent” (49%), “very good” (33%), or “good” (17%). Caregiver education and household income were associated with this future life situation. Nearly 64% of caregivers with a college degree expected their situation to be excellent, compared to 40% of caregivers with some college experience ( $p<.05$ ). More than 6 in 10 families (65%) with household incomes of \$75,000 and above expected overall life situations to be excellent in the future compared to 40% of families with household incomes of \$15,000 or less ( $p<.01$ ).

Similarly, most families were optimistic about their child’s future. Most families expected their child’s overall life situation to be: “excellent” (54%), “very good” (32%), or “good” (12%). With the exception of age at IFSP, none of the child and family characteristics were associated with the family’s perceptions of the child’s future situation. Fewer families of older children at IFSP were optimistic about their child’s future. Nearly two-thirds (63%) of families with children 12 to 24 months of age at IFSP expected their children to have an excellent overall life situation in the future, compared to 47% of families with children over 24 months ( $p<.05$ ).

## Family Experiences Entering Early Intervention in Kansas

Ideally, the process of discovering disability and entering early intervention should be timely and supportive of families. Parents need professionals who attend to their concerns and help gain access to services when needed. Part C of the Individuals with Disabilities Education Act (IDEA) established an early intervention system that was designed to help families by providing a responsive system for (a) identifying children who have or are at-risk for having a disability, and (b) providing a comprehensive and individualized set of services for both children and families. There is almost universal consensus that parent satisfaction constitutes a key component of any evaluation of early intervention services (Bailey, McWilliam, Darkes, Hebbeler, Simeonsson, Spiker & Wagner, 1998; McConnell, McEvoy, Carta, Greenwood, Kaminski, Good, & Shinn, 1998). In this light, families were asked a series of questions on their experiences entering early intervention in Kansas, the types of services offered to their children and their family, and the quality of services rendered.

To trace some of the critical events along a family’s path of entry into early intervention services, families were asked: 1) the age someone first became concerned about the child’s health, development, or behavior, 2) the age of the child when first diagnosed for identification as potentially eligible for early intervention services, 3) the child’s age at referral to early intervention, 4) the age when the family first looked for early intervention, and 5) the age at which the IFSP was signed. The averages for each of these ages are shown in Table 13.

**Table 13. Average Ages of Critical Events Related to EI Entry**

Critical events related to EI entry	Mean age (months)	SE	N
Average age at first concern	10.1	.9	295
Average age at diagnosis	11.8	1.1	295
Average age when family looked for EI	14.2	1.2	293
Average age at referral to EI	15.9	1.0	300
Average age at IFSP	17.4	1.0	305

Children were, on average, under a year at the time of the first concerns and diagnoses and in their second year when families looked for early intervention; when children were referred to early intervention; and when the IFSPs occurred. The average amount of time between first concern and the IFSP was slightly over seven months.

Families were also asked several questions about their experiences entering early intervention. These findings are highlighted in Table 14. According to most families (76%), finding early intervention in Kansas took little to no effort. There were differences, however, between families with children with established risk of developmental delay and those with developmental delay. Approximately 27% of the parents of children with developmental delays reported that it took “some effort” to “a lot of effort” to find early intervention, compared to nearly 10% of parents of children with established risk of developmental delays ( $p < .05$ ). Caregivers with less education also had a more difficult time. Nearly 55% of families with older children (over 24 months at IFSP) had little to a lot of difficulty finding EI compared to only 36% of families with children that were under 12 months at IFSP ( $p < .01$ ). A larger percentage of caregivers with less than a high school diploma (16%) reported it took “a lot of effort” to get early intervention services started relative to those that had a college degree or higher (2%) ( $p < .01$ ). Nearly 30% of families with household incomes between \$15,000 and \$25,000 reported some or a lot of effort to find EI compared to only 14% of high-income families (income over \$75,000) ( $p < .05$ ).

**Table 14. Family Experiences Entering Early Intervention in Kansas**

Family experiences entering EI	Percent	SE	N
<b>Effort to find EI</b>			304
A lot of effort	7.5	1.8	
Some effort	16.0	2.9	
A little effort	27.1	3.5	
No effort at all	49.4	2.5	
<b>Effort to get services started once identified</b>			296
A lot of effort	3.7	2.2	
Some effort	11.1	2.7	
A little effort	40.8	4.7	
No effort at all	44.4	4.5	
<b>Awareness of IFSP</b>			293
Yes	87.0	3.1	
No	13.0	3.1	
<b>Who set IFSP goals?</b>			257
Mostly family	7.9	3.4	
Mostly professionals	11.2	4.0	
Family and professionals	80.9	3.6	
<b>Who determined the kinds of services?</b>			290
Mostly family	3.7	1.3	
Mostly professionals	25.0	3.3	
Family and professionals	71.4	3.4	
<b>Who determined the amount of services?</b>			290
Mostly family	7.5	2.9	
Mostly professionals	44.6	4.6	
Family and professionals	47.9	4.0	

Very few families (4%) indicated that a lot of effort was required to get services started once they had been identified. There were differences, nevertheless, between families with children that were under 12 months at IFSP and those with children over 24 months at IFSP. A little over 26% of families with children over 24 months at IFSP reported “some effort” to “a lot of effort” to get services started once identified, compared to a third (9%) of that proportion of families with children under 12 months at IFSP ( $p<.05$ ). Interestingly, 25% of families with household incomes between \$15,000 and \$25,000 reported some to a lot of effort in getting services started once identified compared to only 10% of the low-income families (annual income less than \$15,000) ( $p<.01$ ).

Although all family interviews were conducted within a few months after an IFSP had been completed and signed, some families (13%) reported that they were not aware of a written plan that described goals for the child and services to be provided. Awareness of IFSP was not related to child or family demographic characteristics.

Families’ level of involvement in deciding a plan for their children’s early intervention services was explored in the interview. When setting goals for the IFSP, there was joint decision-making between families and early intervention professionals in most cases (81%). Poorer families reported less involvement relative to families from higher income brackets. Indeed, 92% of families with household incomes over \$75,000 reported joint decision-making in setting goals and outcomes on the IFSP, compared to 70% of the poorer families (household income less than \$15,000) ( $p<.01$ ). Slightly less joint decision-making was reported (71% joint, 25% mostly professionals) with regard to determining the kinds of services, and an even smaller percentage of joint decision-making was reported for determining the amount of services (48% joint, 45% mostly professionals). The level of shared decision-making was seen differently by caregivers of different education levels. Those with less education were more likely to report joint decision-making. Caregivers with less than a high school degree reported joint decisions on determining the kinds of services 9 out of 10 times (90%), whereas 66% of caregivers with college experience (but less than a BA/BS degree) gave the same response ( $p<.01$ ).

Most families in Kansas reported a fairly effortless entry into the early intervention system. They had little to no difficulty finding EI, getting the services started once identified, and most families were aware that an individualized family service plan had been developed. There was mostly joint decision-making between EI professionals and families in setting IFSP goals and determining the kinds of services and less with determining the amount of service. Families with children with developmental delays had a tougher time finding early intervention compared to those with children with an established risk for developmental delays, and so did families that had older children (those over 24 months at IFSP).

**Services Provided to the Child.** The study collected information on the kinds of services the child and family received in the first months of early intervention. Nearly all (92%) families were receiving some kind of services when they were interviewed (See Table 15). Of those who were receiving services, approximately 91% reported receiving home-based services, 18% were reported to be receiving services in a specialized early intervention program or center, and 4% reported receiving services in a location other than center or home. Families could receive service in more than one setting.

**Table 15. Characteristics of EI Services and Family Perceptions of EI Services on Entry**

<b>EI service characteristics</b>	<b>Percent</b>	<b>SE</b>	<b>N</b>
<b>Families receiving services at time of interview</b>			300
Yes	92.4	2.7	
No	7.6	2.7	
<b>Location of early intervention services</b>			
Home	90.8	2.8	276
Center-based program	17.7	5.1	274
Services elsewhere	3.7	1.3	275
<b>Pattern of service receipt by location</b>			276
Home only	79.2	5.5	
Home + any other location (center or other)	11.6	4.1	
Center only	7.2	2.5	
Center and other location (not home)	0.3	0.3	
Other only (not center, nor home)	1.7	0.6	
<b>Child receives therapy services?</b>			268
Yes	85.7	4.7	
No	14.3	4.7	
<b>Quality of therapy services</b>			213
Excellent	63.6	3.9	
Good	32.3	4.1	
Fair	2.9	1.2	
Poor	0.3	0.3	
Some OK/some not	0.8	0.5	
<b>Rating of amount of therapy services</b>			222
More than needed	2.1	1.4	
About the right amount	77.9	3.6	
Less than needed	17.3	3.8	
Some enough/others not enough	2.7	2.3	
<b>Quality of non-therapy services</b>			150
Excellent	46.3	5.4	
Good	46.2	6.9	
Fair	7.5	3.6	
Poor	--	--	
Some OK/some not	--	--	
<b>Rating of amount of non-therapy services</b>			155
More than needed	2.5	2.2	
About the right amount	87.1	4.6	
Less than needed	10.3	4.4	
Some enough/others not enough	-0	0	
<b>Services child needs but not getting</b>			262
Yes	12.0	3.4	
No	88.0	3.4	



**Table 15. Characteristics of EI Services and Family Perceptions of EI Services Upon Entry (Concluded)**

<b>EI service characteristics</b>	<b>Percent</b>	<b>SE</b>	<b>N</b>
<b>Individualization of services</b>			265
Highly individualized	72.3	4.0	
Somewhat individualized	25.5	3.7	
Not individualized	1.7	0.7	
Mixed	0.5	0.3	
Too soon to tell	12.3	3.4	
<b>Number of professionals working with child</b>			274
Too many	1.3	0.8	
About the right number	91.7	3.1	
Not enough	7.0	3.2	
<b>Communication between professionals</b>			262
Excellent	48.2	4.8	
Good	31.2	4.7	
Fair	10.7	3.5	
Poor	2.4	1.1	
Some OK, Some not	0	0	
Only one professional	7.5	3.9	
<b>Impact of EI services on child's development</b>			275
No impact	4.3	2.1	
Some impact	34.8	3.9	
A lot of impact	48.6	5.4	
Too soon to tell	12.3	3.4	

Nearly 8 in 10 families (79%) reported receiving services in the home only; 12% reported receiving services in the home and another location; 7% reported receiving services in a center-based program only; less than 1% reported receiving services in a program center or other location (but not the home); and nearly 2% reported receiving services in another location only (not a center or home).

Most families (86%) reported that children received therapy services, i.e. speech, occupational, or physical therapy. All high-income families reported receiving some kind of therapy service, compared to 8 in 10 low-income (\$15,000 or less household income) families ( $p < .05$ ).

To examine the extent of parent satisfaction with services, families were asked to rate both the quality and quantity of their services. Families were asked to rate their therapy and non-therapy services separately. They were also asked whether services were individualized to their child's needs, and whether there were services that the child needed but was not getting.

Families were overwhelmingly pleased with the quality and mostly pleased with the quantity of their therapy services. Nearly all families (96%) gave their therapy services a rating of good or excellent. Most but not all families (78%) believed their child was getting the right amount of therapy. Nearly one in 5 (17 %) reported their child was getting less therapy than needed.

There were some interesting trends in the therapy ratings when child and family characteristics were considered. Caregivers with less education were more likely to be satisfied with the amount of therapy provided. Nearly all the families (92%) where the caregivers had a high school diploma felt that the amount of therapy received was the right amount, when compared to 70% of families where the caregiver had some college experience ( $p < .05$ ). Interestingly, more families with children that were very young (under 12 months) at the time of IFSP (76%) gave an excellent rating to the quality of therapy compared to those where the child was in the second year (12-24 months) (55%) ( $p < .05$ ). There were a few families (4%) with children with developmental delays that rated quality of therapy as “fair” or “poor.” In comparison, none of the families with children with established risk for developmental delays ( $p < .05$ ) gave “fair” or “poor” ratings. Furthermore, nearly 1 in 10 (10%) caregivers with less than a high school diploma rated quality of therapy services as fair or poor, while only 2% of those with college experience did so ( $p < .01$ ). Finally, high-income families, those with annual household incomes of above \$75,000, were more likely to rate the quality of their therapy as excellent than were those with incomes ranging between \$15,000 to \$25,000 (71% vs. 44%) ( $p < .01$ ).

Families were also very pleased with the quality and mostly pleased with the quantity of non-therapy services their child was receiving. Nearly all families (92%) gave non-therapy services a rating of good or excellent. Similar to the trend observed in the case of therapy services, most but not all families (87%) believed their child was getting the right amount of non-therapy services. One in 10 (10%) felt their child was getting less of these services than needed. Ratings on quality and quantity of non-therapy services were not related to any child or family characteristics.

Although the proportion was relatively small, some families (12%) reported that there were services that the child needed but was not getting. Of these, the most common were speech therapy, occupational therapy, audiological services, and physical therapy. There were no associations between needing other services and any of the child and family characteristics.

Most families (72%) in Kansas felt that the services were highly individualized to the child's needs. Another 26% thought they were somewhat individualized. Girls were reported as having relatively more individualized services than boys (80 % for girls, 68 % for boys,  $p < .01$ ).

The majority of families reported that the number of professionals working with their children was “about right” (92%). Families were also pleased with how the professionals working with their family communicated with one another. Four out of 5 families thought the communication was “good” (31%) or “excellent” (48%) and another 8% only worked with one professional.

Almost half the parents reported that EI services had had “a lot” of impact on their child's development. These numbers are especially interesting because the child had only been receiving EI a few months when the question was asked. Families with a child with an established risk condition for developmental delay were more likely to report impact of services. Whereas only about 4 in 10 families (44 %) of children with developmental delays reported “a lot of impact,” 66% of families for children with an established risk for developmental delay did so ( $p < .05$ ). Recall that children with established risks for developmental delays tend to enter early intervention when they are younger relative to children with developmental delays so some

of the parent's perception might be tied to the age of the child. Caregivers with different levels of education also perceived the impact of services differently. Nearly all caregivers with less than a high school degree reported that there was "some impact" or "a lot of impact" (96%) on the child's development, in comparison to 71% of caregivers with a college degree or higher ( $p<.01$ ). Similarly, 73% of families with household incomes of \$75,000 or above reported some or a lot of impact of services on the child's development compared to nearly all (95%) of families with household incomes of \$15,000 or less ( $p<.01$ ). Interestingly enough, families with girls (19%) were more likely to report that it was too soon to tell whether EI had an impact on their child's development, compared to those with boys (9%) ( $p<.05$ ) who felt that way.

In sum, most families entering early intervention in Kansas received service in the home and most received some kind of therapy services. Families were overwhelmingly satisfied with the quality of service being provided, and were generally satisfied with the amount of service being provided. Most families saw the services as individualized to the child's needs. A small fraction reported their child was not getting all the services needed. These services were most likely to be speech, physical, or occupational therapy. Despite beginning EI services only a short time prior to the interview, most families reported that EI had either some or a lot of impact on their child. The families most likely to report impact were those with low incomes, families with children with established risk for developmental delays, and those where the caregiver had not graduated from high school.

**Services to Families.** Families were asked a series of questions about the nature of help provided to them through early intervention. Most families in Kansas reported that early intervention programs helped them in various ways (See Table 16).

Families were asked about a number of different kinds of assistance that early intervention programs might have provided. For each, the caregiver was asked to indicate whether the family had received this kind of service. If the answer was no, the family was asked whether they needed this service. Over 6 in 10 families reported receiving help from early intervention programs with regard to the following: learning how to play with, talk with, or teach their child; understanding the child's development and special needs; understanding their legal rights and protections; and including children in regular family routines.

A smaller proportion received help in other areas: finding and paying for respite care; getting information on recreational activities for the child; getting transportation for the children; finding child care; finding and/or paying for medical or dental services; finding out about other agencies and services that may help the child; finding or talking with other families with children with special needs; finding a counselor, minister or other helper; meeting basic household needs; helping with solutions to other problems; and helping to pay for equipment, toys, or therapy. When asked if they needed help in these areas, most families replied that they did not.

The two areas that were identified most frequently as areas where families did not receive help but would have liked it were: finding out about other agencies that might help the child; and finding or talking to other families who have children with special needs. With regard to finding out about agencies, 45% of the families reported having received such information and another 10% would have liked to have received it. Twenty-nine percent of the families were given help in finding families of other children with special needs and another 9% would have liked help in this area.

**Table 16. Help Provided to Families By EI Programs**

Help provided to families by EI programs	Percent	SE	N
<b>Learn how to play, talk with, and teach child</b>			290
Yes	83.9	3.1	
No, and needed this service	4.2	1.3	
No, and did not need	11.9	2.7	
<b>Understand child's special needs</b>			289
Yes	83.6	3.3	
No	5.6	1.9	
Did not need	10.8	3.2	
<b>Understand legal rights and protections</b>			293
Yes	80.1	3.6	
No	6.7	2.7	
No and did not need	13.2	2.6	
<b>To include children in regular family routine</b>			293
Yes	64.9	4.4	
No	1.8	1.1	
No and did not need	33.3	4.4	
<b>Quality of help to family provided in EI</b>			296
Excellent	60.0	4.8	
Good	34.4	4.4	
Fair	3.1	1.5	
Poor	2.2	1.8	
Some OK, Some not	<1	.4	
<b>Effect of EI help and information on families</b>			299
Much better off	54.7	3.4	
Somewhat better off	30.0	3.2	
About the same	11.7	3.2	
Too soon to tell	3.6	2.0	
<b>Find out about other agencies that may help child</b>			287
Yes	44.9	5.1	
No	10.3	3.4	
No and did not need	44.8	5.6	
<b>Program helped pay for equipment/toys/therapy</b>			288
Yes	43.8	4.9	
No	5.6	1.9	
No and did not need	50.6	4.5	
<b>Get information about recreational activities</b>			286
Yes	31.2	4.7	
No, and needed this service	7.9	3.3	
No, and did not need	60.9	5.5	

**Table 16. Help Provided to Families By EI Programs (Concluded)**

Help provided to families by EI programs	Percent	SE	N
<b>Find or talk with other families that have children with special needs</b>			290
Yes	28.5	5.1	
No	8.9	1.7	
No and did not need	62.5	5.0	
<b>Program helped with solutions to other problems</b>			293
Yes	18.6	4.2	
No	4.8	2.5	
No and did not need	76.6	5.2	
<b>Get transportation for child</b>			293
Yes	15.9	5.9	
No, and needed this service	1.8	1.4	
No, and did not need	82.3	6.6	
<b>Find and/pay for respite care</b>			291
Yes	13.9	2.9	
No, and needed this service	7.6	3.2	
No, and did not need	78.4	4.0	
<b>Find/pay for medical/dental services</b>			290
Yes	13.4	2.3	
No	4.1	1.4	
No and did not need	82.5	2.7	
<b>Find child-care for children</b>			291
Yes	11.6	3.5	
No	7.3	3.6	
No and did not need	81.1	3.4	
<b>Find a counselor, minister, or other helpers</b>			292
Yes	10.5	2.3	
No	5.8	2.7	
No and did not need	83.7	3.5	
<b>Meet basic household needs</b>			293
Yes	7.9	2.7	
No	4.3	2.1	
No and did not need	87.7	3.8	

Family income was related to the help families received, with more lower income families reporting that they had received various kinds of assistance. (See Appendix C, Tables C58-C71). A greater proportion of low-income families reported receiving help from early intervention programs in: understanding their child's development and special needs, getting help for respite care, getting information on recreational activities for the child, finding and or paying for medical or dental services, being helped to include children in their regular family routines, and in finding a counselor, minister, or other helper, relative to families in higher income brackets. For example, over 9 in 10 (94%) families with annual household incomes of \$15,000 or below reported they had received help from programs in understanding their child's development and

special needs, compared to 77% of families with higher annual household incomes (\$50,000 to \$75,000) ( $p < .01$ ).

There was also a relationship between level of caregiver education and the kind of help provided by early intervention programs. Caregivers with less than a high school diploma were more likely to have received help in: finding respite care, finding child care, and finding a counselor, minister, or helper, as well as getting help finding food, clothing and shelter, and solutions to other problems their families might have. For example, 23% of caregivers with less than a high school diploma reported receiving help from programs in finding respite care, compared to only 4% of those with a college degree or higher ( $p < .01$ ).

Families were highly satisfied with the services provided to the family. The great majority of families rated those services as “good” (34%) or excellent” (64%). Only 2% of parents rated the quality as poor. How families felt about the quality of service provided to their family did not differ for families with different categories of children or from families with different income or education levels.

When asked about the effect of early intervention help and information provided to families, over half reported their family was “much better off” (55%), and a nearly a third reported their families as “somewhat better off” (30%). Again, these questions were asked when the families had been receiving early intervention services for at most only a few months.

These findings indicate that early intervention programs are providing families with many different kind of assistance and that for the most part, the assistance appears to match well with what the families perceive they need. Families with less income and less education received help in more different areas. Families are very pleased with the services being provided and see them as making a difference for the family.

**Experiences with EI Professionals .** The relationship between the family and the early intervention professionals working with the family is one of the key defining features of the early intervention experience. Several aspects of that experience were explored by the study. These findings are presented in Table 17.

Three-fourths (75%) of the families entering early intervention reported that professionals focused on both strengths and difficulties when talking about their child. There were a few families (9%) that did report that professionals typically focused only on difficulties, while some other families (16%) felt that they focused only on strengths. Furthermore, 15% of families with incomes between \$25,000 and \$50,000 reported that the professionals focus only on difficulties relative to none of the families with incomes over \$75,000 ( $p < .05$ ).

Families were asked whether they used the advice given to them by early intervention professionals about the child’s needs and how to help him or her. More than 8 in 10 (83%) reported that they did so all or most of the time. An association between caregiver education and families’ use of advice by EI professionals was found, with more highly educated caregivers more likely to use the advice. Nearly 87% of caregivers with less than a high-school diploma reported using such advice almost all of the time or some of the time, compared to nearly all (98%) of those with some college experience ( $p < .01$ ).

**Table 17. Experiences with EI professionals and Quality of Services**

Experiences with EI professionals and service quality	Percent	SE	N
<b>In talking about child, professionals focus on</b>			291
Strengths	16.5	2.5	
Difficulties	8.9	3.2	
Strengths and difficulties	74.6	3.4	
<b>Families use advice given by professionals</b>			293
All/most of the time	82.9	3.1	
Some of the time	13.2	2.9	
Hardly ever	0.4	0.3	
NA/no advice	3.6	1.7	
<b>Professionals respect my family's values and background</b>			275
Strongly agree	61.1	3.8	
Agree	38.9	3.8	
Disagree	0	0.0	
Strongly disagree	0	0.0	
<b>Professionals make me hopeful about child's future</b>			275
Strongly agree	61.1	3.8	
Agree	38.9	3.8	
Disagree	0	0.0	
Strongly disagree	0	0.0	
<b>I have good feelings about special needs professionals</b>			275
Strongly agree	64.8	5.1	
Agree	34.6	5.2	
Disagree	0.6	0.4	
Strongly Disagree	0	0.0	
<b>Quality of help to family provided in EI</b>			296
Excellent	60.0	4.8	
Good	34.4	4.4	
Fair	3.1	1.5	
Poor	2.2	1.8	
Some OK, some not	<1	.4	

Families were presented with a series of statements about early intervention professionals and asked whether they agreed or disagreed with the statement. Nearly all the families agreed or strongly agreed that they had good feelings about the early intervention professionals who worked with their family. Families of girls had better feelings about early intervention professionals than families of boys. For families with boys, 61% strongly agreed that they had good feelings about the professionals working with their children, compared to 73% of families with girls ( $p<.01$ ). Upper income families also had more positive feelings about early intervention professionals than did lower income families. Three-fourths of the families (74%) with household incomes of \$75,000 or above strongly agreed that they had good feelings about EI professionals, while only 53% of lower income (\$15,000-\$25,000) families did so ( $p<.05$ ).

All respondents agreed or strongly agreed that professionals respected their families' values and cultural background. There were differences in who agreed and who strongly agreed, with upper income families being more likely to strongly agree. Forty-two percent of low-income families (with household incomes between \$15,000 and \$25,000), strongly agreed that

professionals respected their cultural background and values, whereas nearly twice that proportion (78%) of high-income families (household income over \$75,000) strongly agreed with the statement ( $p < .05$ ).

Only 5% of families agreed or strongly agreed that professionals ignored their opinions. This was not related to any of the child and family demographic characteristics.

Nearly all families agreed or strongly agreed that professionals made them feel hopeful about their child's future. Once again, income was related to how families felt about professionals. About one third of lower income (\$15,000 to \$25,000) families (31%) strongly agreed that professionals made them feel hopeful about their child's future. The comparable figure for families with incomes of \$75,000 or more was 76% ( $p < .01$ ).

The general conclusion derived from these findings was that families in early intervention in Kansas had favorable impressions of EI professionals. Even though families in general perceive the early intervention professionals very favorably, it is somewhat disturbing that early intervention professionals are rated more highly by upper income and more highly educated parents.

The findings on family perceptions at the beginning of the early intervention indicate that most of the families had favorable experiences, and were generally satisfied with the quality and delivery of early intervention services provided to them. Caregiver education and family income were often associated with families' perceptions of their early intervention experiences. It will be important to examine how families' feelings about early intervention change as they have more exposure to the system. It will be equally important to note whether the relationships with caregiver education and family income are sustained over time since these might indicate that the system, although working well for everyone, is working slightly better for families with more resources.

## **Child Care and Community Activities**

Children receiving early intervention services also participate in other activities or programs. One of these is child care. The type and quality of child-care service can be an important influence on child development. Caregivers were asked a series of questions about child care services. They were also asked about community activities in which the child might be participating (See Table 18).

Thirty-seven percent of children entering early intervention in Kansas had received child care at least ten or more hours per week from someone who was not their parent or guardian sometime in the past. When asked if the child was currently receiving child care, 24% of the families indicated their child was.

Nearly all of the children in child care were in only one type of child care arrangement at the time of the interview (93%). About half the children in child care (47%) were there between 31 to 40 hours per week and 17% were there 41 hours or more. When asked about the difficulty in finding child care services, most parents (82%) reported that it was not at all difficult to find appropriate child care, and more than half (54%) reported being "very satisfied" with how their child care arrangement met the child's needs.



**Table 18. Characteristics of child care arrangements and services for children and families in early intervention**

Child care characteristics	Percent	SE	N
<b>Received child care in past</b>			292
Yes	36.9	4.5	
No	63.1	4.5	
<b>Receiving child care now</b>			75
Yes	24.2	3.1	
No	75.8	3.1	
<b>Number of current child care arrangements</b>			74
One	92.7	3.5	
Two	3.9	2.4	
Three or More	3.4	1.7	
<b>Total Time in Child Care (Hours Per Week)</b>			72
1 to 30	36.5	8.3	
31 to 40	46.8	10.7	
41 or above	16.8	5.4	
<b>How hard to find appropriate child care</b>			74
Very/Somewhat difficult	18.0	5.7	
Not at all difficult	82.0	5.7	
<b>Satisfied with child care's ability to meet needs</b>			74
Very Satisfied	53.7	10.3	
Satisfied	34.9	11.1	
Somewhat /Very dissatisfied	11.4	6.9	
<b>Does child go to any other group activity</b>			290
Yes	28.2	7.1	
No	71.8	7.1	
<b>If Yes, Other Group Activity</b>			80
Play group/babysitting	69.2	9.9	
Story hour	10.9	4.4	
Sunday school/church	22.1	7.0	
Lessons	13.8	6.3	
Preschool	7.9	5.2	
Nursery school	0.5	0.7	
Day care	2.7	1.6	

Parents also were asked if the children regularly went to any other form of group activity. Most (72%) said their child did not. Of those parents who did respond positively to this question, the most frequent other group activity was a play group or occasional babysitting (69%).

Participation in child care or community activities did not vary for children from different family backgrounds or with different child characteristics.

### **3. CONCLUSIONS**

Who are the children and families that receive early intervention services in Kansas? A snapshot of this population as they begin services for the first time reveals some interesting findings:

- Children entering early intervention in Kansas are more likely to be male than female.
- About one in five is a member of a minority group.
- One in 20 is in foster care but this is a lower percentage of children in foster care than in the national early intervention population.
- Children enter early intervention in Kansas at every point throughout the first three years of life, but are more likely to enter in the first, and especially, in the third year of life.
- The average age when someone was first concerned about the child was 10 months, and the average age at first IFSP was 17 months.
- Children enter early intervention for a wide variety of problems, but a common thread is that most have difficulties related to speech and language.
- The majority of children are eligible for services because of a developmental delay. These children typically enter early intervention in Kansas in their third year. On the other hand, most children receiving services because of an established risk for developmental delay enter early intervention in their first year.
- Children entering early intervention in Kansas in their first year are more likely to be medically involved, as indicated by their birth history, need for medical devices, and prescription usage. They are also more likely to have motor problems than children who enter at later ages.

With regard to families of children who receive early intervention, it was found that:

- One in five families have household incomes of less than \$15,000 per year.
- One in ten have a primary caregiver who did not finish high school.
- Most have two adults in the household and most have other children in addition to the child receiving early intervention.
- Slightly less than half of the caregivers were employed, as were almost all of their partners.

With regard to the nature of early intervention services received in the first few months after the initial IFSP:

- Nearly all children and families received services in their home. One in five received services in a center.
- Most were receiving therapy services.

Families' initial experiences with early intervention services were good:

- Families had a relatively effortless entry into the EI system.
- Most were aware of the IFSP and felt they had been involved in the decision-making.
- Families were generally pleased with the quality and quantity of therapy and non-therapy services provided.
- Despite having been interviewed only months after their entry into EI, families reported that EI had an impact on their child's development.
- Families had already received many different kinds of help from their EI program, were happy with the professionals they dealt with, and reported being better off as a result of EI.

The findings described above suggest that early intervention in Kansas is serving many different kinds of children and families, and families' experiences with the system are very positive. There were, however, some interesting relationships with caregiver education and family income that emerged across a number of areas. Both of these are indicators of the resources available to a family, and they tend to be highly correlated, with caregivers with lower education levels being part of families with lower household incomes.

The impact of family resources can be seen in the characteristics of the children receiving early intervention. Childhood poverty is associated with a variety of detrimental effects on children's development, including, physical health, cognitive ability, school achievement, emotional and behavioral outcomes (Brooks-Gunn & Duncan, 1997). Furthermore, poverty has been the one factor most consistently related to child abuse and neglect (Sedlak & Broadhurst, 1996). Therefore, it was no surprise to find that families with lower household incomes were more likely to have low birth weight babies, and to have children in poorer health and use medications. They also were less likely to have health insurance coverage. Also, predictably, families with fewer resources were less likely to report that their child's overall life situation was excellent.

Families with more limited resources received more kinds of assistance from early intervention programs, which could reflect the system's sensitivity to family need. With regard to satisfaction with early intervention, families with limited resources, interestingly enough, were more pleased with some aspects of early intervention. Caregivers with less education were more likely to report their child was receiving the right amount of therapy. They were also more likely to report that the services had had an impact on their child.

There were also, however, several indications that the early intervention system is possibly working less well for families with limited resources. Caregivers with less education had a more difficult time getting early intervention services started. Lower income families reported less joint decision-making between families and professionals. Children in lower income families were less likely to receive a therapy service (i.e., speech, occupational or physical therapy). Caregivers with less than a high school education were less satisfied with the quality of their therapy. Lower income families had less positive feelings about professionals than did upper income families. They were less likely to agree that professionals respected their cultural background and values, and less likely to report that professionals made them feel hopeful about their child's future. These differences need to be considered against the overall finding that families of every income and education level reported positively on their early intervention experiences thus far. Those with limited resources were slightly less positive in some areas.

In conclusion, the early intervention system in Kansas is serving children with a variety of developmental needs who are entering the program at every age point between birth and 36 months of ages. The families of these children are equally diverse, and represent a range of income and education levels. Most families are receiving services in their homes, and they are pleased with the services and their interactions with professionals during their first few months of early intervention. There were several indications that the early intervention system may be working somewhat less well for families with limited resources.

The purpose of this report was to provide descriptive information about who is being served by early intervention in Kansas. Some of the most interesting questions to be addressed by a longitudinal study of this kind will be answered with subsequent reports that will discuss children and families a year after the first IFSP and as the child reaches 36 months of age. These subsequent analyses will look at the kind of developmental progress being made by children and which children continue to require services in the years to come. These analyses will look specifically at some of the characteristics described in this report to identify which children and families experience the most positive outcomes after early intervention.

## **Next Steps**

Additional findings from the Kansas Early Intervention Longitudinal Study will be summarized in a series of reports over the next few years. The next report will focus on the nature of early intervention services provided to children and families. Later reports will look at child and family outcomes and the characteristics of service providers and early intervention programs.

## APPENDIX A

### Methods

The child sample for KEILS consists of 68 families recruited as part of the National Early Intervention Longitudinal Study (NEILS), and an additional 248 families recruited to supplement that sample. In this section, we describe the sampling procedures for selecting the KEILS county networks and families; the weighting procedures that enable us to generalize from the sample to children and families who enroll in Part C early intervention programs within the state; the source of the enrollment data reported; data analysis procedures; and limitations of the data.

### Sampling Procedures

#### County Network Sample

In Kansas, counties are organized into networks for purposes of enrolling children in early intervention and administering these services. Typically, counties with large populations comprise their own network, and smaller counties are aggregated into networks. A few counties with very small enrollments are split between networks.

For the KEILS sample, networks were selected as the local sampling unit. Four counties/networks were selected for the national study. These same four networks and an additional 17 networks were included in the supplemental sample for a total of 21 networks for the supplemental sample. Networks were selected randomly, with the probability of selection being proportional to the number of children served in the network in 1999, with the additional criterion that there be at least 10 children served annually under Part C in a county. This latter provision was necessary to assure a level of efficiency and cost-effectiveness in sample recruitment. The total Part C enrollment for these networks in 1999 was 2,748 children (comprising 69.5% of the total of 3,955 children served in the state as a whole).

#### Child Sample

The data presented in this report are based on a state representative sample of families who entered early intervention in Kansas for the first time between April 15, 1997 and January 19, 2000. The families recruited as part of the national study had Individualized Family Service Plan (IFSP) dates ranging from 9/15/97 to 5/19/98. The additional families had IFSP dates ranging from 3/30/99 to 1/19/2000. Each network was assigned a number of children and families to recruit for the study. That number was based on the number of children served in early intervention in the network in 1999.

Two samples were used in the analysis. The first sample, referred to as the enrollment sample, is the sample on which a few of the analyses in this report are based. The enrollment sample includes all children who lived in the sampled networks<sup>1</sup> and were being enrolled in Part

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<sup>1</sup> Children who had previously received early intervention were excluded from the enrollment data collection. Multiple children from the same family were included in the enrollment sample, although not in the study sample, as long as all children were being enrolled for the first time during the recruitment period.

C early intervention for the first time<sup>2</sup> during their county's recruitment period. This sample includes 595 children. Minimal demographic information was collected for this sample.

A second sample, which is a subset of the first, was used in the majority of the analyses in this report; it is referred to as the study sample. These are children who met criteria for study participation and had an adult's written consent for the child's and family's participation in the study. In addition to meeting the criteria for the first sample, to be eligible for the study participant sample the child and family were required to:

- Be less than 31 months of age at the time the IFSP was signed.
- Have an English- or Spanish-speaking adult in the household who could answer questions about the child and family.
- Be the only child in the family recruited for the study (siblings and other children of multiple birth sets were excluded).

There were 316 children in this sample<sup>1</sup>.

## **Data Sources**

The data in this report are drawn from two sources: an enrollment form and a family interview. Early intervention personnel in sampled networks who enrolled families into early intervention were asked to complete a *NEILS Family Information Form A* (Exhibit A-1) for all children who enrolled in early intervention during their network's study recruitment period. Local personnel were asked to complete an enrollment form within 30 days of each family's IFSP. Completed forms were mailed to SRI, where they were reviewed for completeness and processed for computer analysis. There was no personally identifying information on these forms. An additional form was completed for children who met the criteria for the study sample and whose parents agreed to participate in the longitudinal study.

Of the 595 families that completed enrollment forms, 501 were eligible for the study (i.e., had a child under 31 months of age and an adult in the household who spoke English or Spanish.). Of the 501 eligible, 316 families agreed to participate in the study for an agreement rate of 63%. When a family agreed to be in the study, their name, address, and phone number was sent to SRI<sup>2</sup>.

Within 16 weeks of the study enrollment, sample families were interviewed. These interviews could be completed up to four months from the date of the IFSP although most (67 %) were completed within the first two months. RTI was able to contact 305 of the 316 families (96.5 %) for this first interview.

## **Sample Weighting Procedures for the Enrollment Sample**

Two weights were calculated for each child enrolled in early intervention in sampled networks during the enrollment period for whom Form A enrollment data were provided:

- Weight 1 (denoted W1) was the value necessary to project the enrollees in each sampled network to the total number of early intervention enrollees in that network during an entire year.

- Weight 2 (denoted W2) was the value necessary to project the total number of enrollees during a year in the sampled network to the total number of enrollees in the state on December 1, 1997.<sup>3</sup>

The final Form A weight for each sample enrollee was the product of these two weights (that is,  $W1 \times W2$ ). The procedure for determining each weight is described below.

### **Weighting the Enrollment Sample to Network Totals**

The first step in weighting the enrollment sample was to weight the enrollees in each sampled network to the total number of early intervention enrollees in that network during a one-year interval. For example, if there were 20 sample enrollees in a network and we had estimated that during a year the network would enroll 200 early intervention participants, then the first weight (W1) for each sample enrollee in the network would be 10. We estimated the number of children enrolled in each network in a one-year period as one-third of the number enrolled in 1999. (This probably underestimates enrollment, since children drop out and age out of the program; however the number who enroll in a year will be proportional to the enrollment in 1999, and for weighting and analysis purposes it was only necessary that the estimated yearly enrollments be proportional to the actual yearly enrollments).

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<sup>2</sup> The Department of Health and Environment contacted the 21 networks and enlisted their participation in the study. SRI mailed recruitment materials and forms to each of these networks. The Department arranged a conference call with the sites and SRI to explain recruitment and answer questions about the process. Each network was given a target number of children to recruit for the study. These targets added up to 281 children. Once recruitment began, each site faxed the IFSP log which is part of the recruitment package to SRI on a schedule determined by SRI. Sites also mailed completed enrollment forms to SRI as they recruited families into the study. SRI monitored the progress of enrollment and reported back to the state on a bi-weekly basis. Recruitment for the supplemental sample began in April 15, 1999. It had been scheduled to end in June 1999 but because sites had not yet reached the target number, recruitment was extended by several months. Recruitment ended on Jan 19, 2000. Although only 248 of the 281 children were recruited, it was decided to end recruitment because it had already extended far beyond the original end date and because the number of families recruited although slightly less than ideal was adequate to generate reliable state-wide estimates.

<sup>3</sup> December 1 is the date on which the state child count is taken for federal reporting purposes.

## Exhibit A-1. NEILS family information form—Form A

Complete for EVERY family who resides in this county and who have completed their first IFSP.

1. Child's date of birth (*MM/DD/YY*) \_\_\_\_\_
2. Child's gender (*Circle one number*)                      1----Female      2----Male
3. Is child of Hispanic origin? (*Circle one number*)      1----Yes      2----No      3----Don't know
4. Child's race (*Circle one number*):  
            1----White              2----Black or African American              3----American Indian or Alaskan Native  
            4----Asian or Pacific Islander              5----Other \_\_\_\_\_              6----Don't know
5. Is child in foster care? (*Circle one number*)                      1----Yes      2----No
6. Does family have a working phone at home? (*Circle one number*)                      1----Yes      2----No
7. Does family receive any kind of public assistance? (*Circle one number*)      1----Yes      2----No
8. Reasons for child's eligibility for early intervention services (*Circle one number*)  
            1----Diagnosed condition--Please specify: \_\_\_\_\_  
            2----Developmental delay--Please describe: \_\_\_\_\_  
            3----At risk--Please describe: \_\_\_\_\_
9. Date of referral for early intervention services (*MM/DD/YY*) \_\_\_\_\_
10. Date IFSP signed/completed (*MM/DD/YY*) \_\_\_\_\_

### NEILS INVITATION CRITERIA

1. Was the child younger than 31 months old on the date the IFSP was signed? (*Circle one number*)  
    1----Yes                                      2----No
2. Is there an English- or Spanish-speaking adult in the household to respond to a phone interview? (*Circle one number*)  
    1----Yes                                      2----No
3. ONLY ONE CHILD PER FAMILY IS ELIGIBLE FOR NEILS. Is this **the only child** from this family starting early intervention **OR** if there are multiple children from the same family in early intervention, is this the **one child** eligible for NEILS (per instructions on pages 5-6 of the NEILS Enrollment Procedures Manual)?  
    1----Yes                                      2----No

o If **YES** to **ALL** of the criteria above, invite the family to participate in NEILS.  
Go to the NEILS Enrollment Form-Part B.

o If **NO** to **ANY** of the criteria above, the family is not eligible for NEILS.  
STOP HERE. Return forms to the NEILS Enrollment Coordinator for your site for mailing to SRI.

**Questions? Call the NEILS Hotline toll free: 1-800-682-9319**



## **Weighting Form A Enrollments to the Kansas Total**

The estimated numbers of enrollees in sampled networks over a 1-year period were weighted to state totals of the number of early intervention participants on December 1, 1999, via a four-step process:

1. The inverse of the probability of network selection was calculated for each selected county, denoted as  $Y$ . For example, if the probability of selecting a particular network was 20%, then the inverse would be  $Y = 5$ . (Networks were originally selected from a state with probabilities that were proportional to the number of early intervention enrollees in 1999. Consequently, large networks tended to have larger probabilities of selection and smaller  $Y$  values, and vice-versa for small networks. However, networks with fewer than 10 estimated early intervention enrollees were not candidates for selection for budgetary reasons.)
2. The quantity  $W1 \times Y$  was calculated for each sample enrollee and summed over all enrollees in the state, denoted as  $Z$ . This is an estimate of the number of early intervention enrollees per year in the entire state.
3. Let  $Q$  denote the total number of early intervention participants in the state on December 1, 1999. The quantity  $(Q/Z)$  was calculated. This is a ratio of the estimated number of early intervention participants in the state on December 1, 1999, to the estimated number of yearly enrollees in the state.
4. The second weight was calculated as  $W2 = (Q/Z) \times Y$ . This weight projects the number of yearly enrollees in the sampled networks during an entire year to the number of early intervention participants on December 1, 1999.

## **Sample Weighting Procedures for Study Sample for the Family Interviews**

A total of 595 children were enrolled in the study and had corresponding Form A data and weights, which projected to a state total of 3,955. Families of these children were contacted for the purpose of completing the initial family interview. A total of 305 family interviews were completed. The respondents to the family interviews were weighted to be representative of the same universe as represented by the 595 children who had Form A data.

The weighting procedure for the family interviews was as follows:

1. Demographic variables from the Form A data collection instrument that were believed to be important to study outcomes were identified. These included: 1) the child's age at IFSP (in 6 month intervals), 2) the child's age in months at referral for EI (in 6 month intervals), 3) the child's gender, 4) whether the family had a working telephone at home, 5) whether the family received public assistance, 6) whether the child was in foster care, and 7) the inferred reason for eligibility (i.e., developmental delay, a diagnosed condition other than delay, or at risk of delay).

2. The set of Form A respondents who were eligible for the family interview were identified. This group excluded children who were 31 months of age or older and siblings of children who were randomly selected from within their family to be the subject of the family interview questionnaire. There were a total of 501 eligible Form A respondents, who projected up to 83.6% of the original universe.
3. The Form A weight was applied to the Form A respondents who were eligible to receive the family interview to estimate the marginal distribution for each of the demographic variables in the portion of the universe that they represented.
4. The family interview respondents were initially assigned the child's Form A weight. The marginal distributions on the demographic variables were computed and compared to the estimated marginal distributions for the corresponding portion of the universe. The calculated percentages were generally close, but could be improved by modification of the weights.
5. To minimize any differences in marginal distributions, the Form A weights for the family interview respondents were modified to match the estimated marginal distribution in the universe as closely as possible. Deming's algorithm was applied iteratively to adjust the weights. Finally, the largest 5% of weights were truncated at the 95<sup>th</sup> percentile of the weights to insure that sampling efficiency was not unduly diminished.

This process produced weights for the family interview respondents so that they were representative of the corresponding portion of the universe that was eligible to receive the family interview with respect to all of the aforementioned demographic characteristics.

Exhibit A-2 shows the weighted totals for the demographic variables used in the weighting of the family interviews. The first column shows the estimates for the universe of children at the time of enrollment. The second column shows the estimates for the universe of children who would have been eligible for the Family Interview Survey (had all of the children in the universe been enrolled in the study). The major difference between these two distributions is in the age of the child, since some of the children who were enrolled between the ages of 31 to 36 months were ineligible for the study sample. The third column shows the distribution of the demographic variables for that portion of the universe represented by the Family Interview respondents (i.e., using the Form A weights). Differences between the distributions in the second and third column are indicative of response bias and are quite small. The most important differences are 1) a decrease in the number of Hispanics (from 8.9% to 6.7%), 2) a decrease in the percentage of families who do not have a functioning telephone at home (9.8% to 6.0%), and 3) a decrease in the percentage of children in foster care (5.0% to 4.2%). The last column shows the distribution of the Family Interview respondents after their weights have been adjusted to reduce differences associated with non-response. For example, the adjustments modifies the percentage of children who are Hispanic to 8.9%, the percentage with no working telephone to 9.7%, and the percentage in foster care to 5.0%. The weights used for the last column are those that are used for all subsequent tabulations of Family Interview respondents.

## Exhibit A-2. Comparison of distribution of demographic variables

Demographic Variable	Form A Respondents with Form A weights	Form A Respondents Eligible for Family Interview Survey	Family Interview Respondents With Form A Weights	Family Interview Respondents With FI Weights
Unweighted Total	595	501	305	305
Weighted Total	3,955	3,308	2134	3308
<b>Child's age in months at IFSP signing (percent)</b>				
Birth to < 12 months	30.8	34.8	35.9	34.8
12 to < 24 months	26.8	31.0	28.5	31.0
24 months and older	42.4	34.2	35.6	34.2
<b>Child's gender (percent)</b>				
Male	66.4	65.2	64.7	65.2
Female	33.6	34.8	35.3	34.8
<b>Child's race (percent)</b>				
White	76.7	78.1	80.0	78.4
Black	7.8	7.9	8.0	7.9
Hispanic	10.4	8.9	6.7	8.9
Other	4.7	4.8	5.3	4.8
Missing	0.5	0.4	0.0	0.0
<b>Does family have functioning phone at home? (percent)</b>				
Yes	89.7	90.1	94.0	90.3
No	9.1	9.8	6.0	9.7
Unknown	1.2	0.1	0.0	0.0
<b>Does family receive public assistance? (percent)</b>				
Yes	38.5	39.1	38.5	39.5
No	60.6	60.2	61.5	60.5
Unknown	1.0	0.8	0.0	0.0
<b>Is child in foster care? (percent)</b>				
Yes	4.5	5.0	4.2	5.0
No	92.5	95.0	95.8	95.0
<b>Inferred reason for eligibility (percent)</b>				
Developmental delay	74.3	71.2	70.2	71.4
Established risk for developmental delay	24.5	27.8	29.0	27.8
Unknown	1.2	1.0	0.9	0.8

## Data Analysis Procedures

All data were analyzed by using SUDAAN (Shaah, Barnwell, and Bieler, 1997). Standard errors in SUDAAN were estimated by the method of pseudo-replication. Twenty-three replicate samples were generated. Each sample consisted of approximately half of the networks. Replicates were balanced in the sense that all networks appeared in 11 of the replicates. Separate weights were calculated for each replicate with the same procedure as was used for the full sample.

The data tables included in this report present data for the full study sample of infants and toddlers with disabilities and for important subgroups (e.g., children who were eligible for early intervention for different reasons). Most of the variables presented in the tables are reported as weighted percentages of the children in the full sample or in the subgroups. In some cases, rather than percentages, the figures refer to means, such as the mean age at which children entered early intervention. Percentages and means are weighted to represent the state population of children entering early intervention. However, the percentages and means are only estimates of the actual percentages and means that would be obtained if all children entering early intervention were included in the study. These estimates vary in how closely they approximate the true measures that would be derived from a study of all children entering early intervention. To aid the reader in determining the precision of the estimates, for each percentage and mean the tables present the approximate standard error and the unweighted number of cases on which the statistic is based.

To determine the precision of a particular percentage or mean, the reader can construct a confidence interval for the estimate by multiplying the standard error by 1.96. The result is the range around the estimate within which the true measure would be found 95 out of 100 times. For example, the study estimates that 66.4 percent of children receiving early intervention in Kansas were male. The standard error of that estimate, 3.8, is multiplied by 1.96, letting us assume with 95% confidence that the true percentage of males falls within a range of  $\pm 7.45$  percentage points, or 58.95 to 73.85 percent. The standard errors associated with the data are contained in tables in the Findings section or in Appendix C.

Readers also may want to compare percentages or means for different subgroups to determine, for example, whether there is a statistically significant difference in the average age at enrollment into early intervention between children who are eligible because of a developmental delay and those who are eligible because of a diagnosed condition. To calculate whether the difference between two values is statistically significant with 95% confidence (denoted as  $p < .05$ ), the squared difference between the two values of interest is divided by the sum of the two squared standard errors. If the result is larger than 3.84, the difference is statistically significant. Presented as a formula, a difference between two values is statistically significant at the .05 level if:

$$\frac{(V_1 - V_2)^2}{SE_1^2 + SE_2^2} > 1.96^2$$

where  $V_1$  and  $SE_1$  are the first value and its standard error and  $V_2$  and  $SE_2$  are the second value and its standard error.

In comparisons between two or more groups, the level of significance of the differences between the groups is indicated in the text.

## **Data Limitations**

As explained in the introduction to the report, the most notable limitation on the data reported here involves the potential for bias resulting from incomplete data. SRI made every effort to obtain enrollment information for every family that lived in the sample networks and enrolled in early intervention for the first time during the study recruitment period. However, there was one main reason that we did not receive information for all such families.

Every effort was made by SRI to obtain enrollment information for every family that lived in the sample counties and enrolled in early intervention for the first time during the study recruitment period. However, one of the reasons for incomplete data was uneven adherence to study recruitment procedures by some enrolling programs. Despite the importance placed on completing the data form from all families, we have reason to believe that some early intervention personnel did not complete forms for all families. SRI worked with the sites throughout the recruitment period to minimize these problems, but we do suspect that there were some families for whom data forms were not completed. We have no particular reason to believe that such families differ in any systematic way from families for whom we do have data. To the extent this is true, there should be no bias introduced by the resulting incompleteness of information.



## **APPENDIX B**

### **Coding of Disability Terms**

#### **Coding System**

The National Early Intervention Longitudinal Study (NEILS) research team developed a system to code the terms supplied by providers to describe the reason why the child was eligible for early intervention. The coding system is based on the premise that infants or toddlers who are eligible for early intervention services manifest delays in basic domains of development, or are eligible for services due to the presence of a condition that serves as a proxy for developmental delay, or are subject to environmental factors that are highly associated with developmental delay. The basic domains of development where delay is manifested are associated with limitations of body or organ functions (e.g. sensory, motor, mental) or manifested as limitations in the performance of skills and activities (e.g., learning, communication, self-help, social interaction).

Developmental delay comprises the primary assignment that is the established basis for eligibility for early intervention under federal guidelines. Assignment to the developmental delay category assumes that some form of measurement has been made that meets the criteria established for developmental delay in that state (Shackelford, 1998). Eligibility criteria for intervention in most states are based on documentation of one or more of three forms of evidence: (a) impairments of function and/or limitations in performance of activities as measured by deviation units or percentage deficit; (b) specific medically diagnosed conditions known to be associated with developmental delay; or (c) the presence of biological or environmental factors that place children at-risk for developmental delay.

Coding the reasons for eligibility for Part C services is based on the premise that the eligibility terms provide evidence of at least one of these three aforementioned forms. A preliminary review of a sample of 225 terms from Form A (the Family Enrollment Form) revealed 130 distinct, codeable terms, and that no single available coding system was sufficient to code a majority of terms. Of the classification systems reviewed, the International Classification of Impairments, Disabilities, and Handicaps (ICIDH, WHO, 1980; ICIDH-2, WHO, 1997) captured the majority of terms related to impairments of function and/or limitations in performance of activities, which is most closely related to the various developmental delay criteria. The International Classification of Diseases, 9th Revision (ICD-9, 1999) system permitted coding of medically diagnosed conditions and biological risk conditions such as prematurity. Environmental risk factors were coded using V codes as summarized in The Classification of Child and Adolescent Mental Diagnoses in Primary Care (DSM-PC) (Wolraich, Felice, & Drotar, 1996) and detailed in the ICD-9.

#### **Coding Process**

A decision tree was developed for use in the coding (See Table B-1). The coder used the decision tree to review the reason(s) documenting eligibility of a particular child and to assign appropriate codes from the selected classification systems. The use of the decision tree was accompanied by summary charts for the ICIDH (WHO, 1980, 1997) for specific impairments and activity limitations; the ICD-9 for medically diagnosed conditions, and the DSM-IV PC (Wolraich, Felice, & Drotar, 1996) and ICD-9 (1999) V codes for environmental risk

characteristics. To code the reason for a given child's eligibility, the term(s) written by the early intervention provider were reviewed sequentially for applicability to the guiding questions A through D. If the answer to the first guiding question was affirmative, the term was coded using the item and sub-item that is applicable using either the alphabetized or numbered summary chart of specific codes. If the answer was negative, the coder proceeded to the next guiding question to examine applicability.

A research assistant familiar with eligibility terms and the various coding systems reviewed all of the terms provided by providers for each participating child. Codes were entered directly into a database that was used to create the file for data analysis. Approximately 7,000 terms were coded. These codes were used to electronically generate a systematized code list based on the question hierarchy (Table B-1). An independent coder checked a random sample consisting of about half the terms using the generated code list and the ICD-9. Computer programming was used to check codes for consistency, insuring a near perfect level of accuracy. Three members of the research team reviewed questionable terms to determine codability. The resulting frequencies for the finest level of the coding system are shown in Table B-2.

### **Recoding of Eligibility Categories**

The research team developed a second coding system to classify the provided descriptor terms as developmental delay, diagnosed conditions, or at-risk for developmental delay for the national study. Although the providers had indicated the child as being eligible based on one of these criteria, the inconsistency with which these three categories were applied led the researchers to suspect the utility of the data. To insure consistent usage, the research team re-classified each child under one of the three eligibility conditions based on the descriptor terms provided.

The complete list of terms was circulated among four members of the research team and each indicated independently which of the three eligibility conditions applied to each term. Any terms upon which the team did not agree were then discussed until a consensus was reached as to how it should be classified.

It is important to keep in mind that since Kansas does not serve children at risk for developmental delays, only two eligibility categories were used with data in this report. Thus, to be more consistent with state terminology, 'diagnosed condition' was referred to as 'established risk for developmental delay'. Thus, the children originally classified as at-risk in this group, were combined with children with a 'diagnosed condition' to form the established risk for developmental delay group. The classification applied to each of the terms for the Kansas group is shown in the last column of Table B-2. These are the basis for the findings related to eligibility described in the report.



**Table B-1. Question hierarchy for coding reasons for receipt of early intervention**

A. Does the reason documenting eligibility describe a significant variation in development, form, or function of physical, sensory, motor, physiological, neurological, or psychological systems? A significant variation includes delay, loss, restriction, impairment, and deficiency of development of function.

No [Go to question B.]

Yes



**CATEGORY I**

- A: Development
  - Development – Mental
  - Development – Physical
- B: Somatic systems
- C: Sensory Systems
  - Sensory Systems: Vision
  - Sensory Systems: Hearing
- D: Motor Systems
  - Motor Systems: Gross
  - Motor Systems: Fine
  - Motor Systems: Oral
  - Motor Systems: Apraxia
- E: Physiological Systems
  - Physiology: Cardiovascular
  - Physiology: Respiratory
  - Physiology: Digestive
  - Physiology: Endocrine/metabolic
  - Physiology: Urological
  - Physiology: Lymphatic/hematol/immunologic
- F: Neurological
- G: Psychological
  - Psychological: Intellect/cognitive
  - Psychological: Affective
  - Psychological: Language

**Table B-1. (Continued)**

B. Does the reason documenting eligibility describe a limitation or delay in the performance of one or more activities of daily life?

No [Go to question C.]

Yes



**CATEGORY II**

- I: Learning
- J: Transferring Body
- K: Moving Around
- L: Communication
- M: Self-Help
  - Self-Help: Daily living
  - Self-Help: Toileting
  - Self-Help: Feeding skills
  - Self-Help: Instrumental activities: Daily living
- N: Social Interaction
- O: Behavior
  - Behavior
  - Behavior: With objects
  - Behavior: With people
- P: Other Specified

C. Does the reason for documenting eligibility describe specific health conditions, syndromes, or diagnoses associated with delayed or atypical growth or development?

No [Go to question D.]

Yes



**CATEGORY III**

- Q: Congenital Disorders
  - Congenital: Chromosomal/gene
  - Congenital: Other anomaly
- R: Prenatal/Perinatal Factors
- S: Infections
- T: Other Illness/Injury
- U: Chronic Diseases/Neoplasms
- V: Musculoskeletal Disorders
- W: Central Nervous System Disorders
- X: Other Specified

**Table B-1. (Concluded)**

D. Does the reason for documenting eligibility describe environmental factors (i.e., lack of, atypical, restricted, etc.) highly associated with risk for delayed or atypical development?

No

Yes



**CATEGORY IV**

- Y: Physical Environment
  - Physical Environment
  - Physical Environment: Product/objects/materials
  - Physical Environment: Immediate environment
- Z: Social Environment
  - Social Environment
  - Social Environment: Family/caregivers
- AA: Cultural Environment
- BB: Communal Infrastructure/Environment
  - Communal Environment: Education
  - Communal Environment: Social services
  - Communal Environment: Health services
- CC: Other Specified
- DD: Unspecified

**Table B-2. Disability descriptors and corresponding inferred eligibility codes**

Disability Descriptors	Inferred Eligibility Codes <sup>a</sup>
Group_A: Development	
ALG A: Development	
315.5: Mixed development disorder	2
315.9: Developmental disorder, NOS	2
ALG Aa: Development: Physical	
Aa: Development: Physical	2
783.4: Lack of expected physical growth	2
Group_C: Sensory Systems	
ALG C: Sensory Systems	
C: Sensory Systems	1
ALG Ca: Sensory Systems: Vision	
365.9: Glaucoma	1
368: Vision impaired, blind	1
ALG Cb: Sensory Systems: Hearing	
389.9: Hearing loss, deaf	1
Group_D: Motor Systems	
ALG Da: Motor Systems: Gross	
315.4: Gross motor delay, coordination	2
ALG Db: Motor Systems: Fine	
a306: Fine motor	2
Group_E: Physiological Systems	
ALG Ea: Physiology: Cardiovascular	
401.9: Hypertension	1
416: Pulmonary hypertension	1
427.89: Bradycardia, tachycardia	1
ALG Ec: Physiology: Digestive	
530.81: Gastroesophageal reflux, GERD	1
560: Bowel	1
ALG Ed: Physiology: Endocrine/metabolic	
263: Malnutrition	1
Group_G: Psychological	
ALG Ga: Psychological: Intellect/cognitive	
299.8: PDD, pervasive development disord	1
299: Autism, Asperger's syndrome	1
314: Attention deficit	2
314.01: ADHD	2
i00400: Cognitive, cognition	2
ALG Gc: Psychological: Language	
315.3: Developmental speech/language	2
315.31: Expressive language delay	2
315.32: Receptive language delay	2
315.39: Articulation, phonological disorder	2
Group_L: Communication	

<sup>a</sup> This column shows how the reasons for eligibility were classified by the research team: 1= Established Risk for Developmental Delay, 2 = Developmental Delay

**Table B-2. (Continued)**

Disability Descriptors	Inferred Eligibility Codes <sup>a</sup>
ALG L: Communication	
a201: Communication delays, disorders	2
Group_M: Self-Help	
ALG M: Self-Help	
a500: Adaptive self- skills	2
Group_N: Social Interaction	
ALG N: Social Interaction	
a700: Social skills, psycho-social	2
Group_O: Behavior	
ALG O: Behavior	
D19: Behavior concerns	2
Group_Q: Congenital Disorders	
ALG Qa: Congenital: Chromosomal/gene	
758: Down Syndrome, Trisomy 21	1
758.2: Trisomy 18	1
758.3: Cri-du-chat syndrome	1
758.5: Trisomy 8, trisomy 2	1
758.7: Klinefelter's syndrome	1
758.9: Other chromosome/genetic anomaly	1
759.89: Other spec congenital syndrome	1
ALG Qb: Congenital: Other anomaly	
743.3: Congenital cataracts	1
743.9: Optic dysplasia or hypoplasia	1
745.2: Tetralogy of Fallot	1
746.87: Malposition of heart	1
746.9: Unspecified heart anomaly	1
747: Other congen circulatory anomalies	1
748: Choana atresia	1
749: Cleft palate	1
749.1: Cleft lip	1
750.3: Tracheal esophageal fistula (TEF)	1
756.7: Anomalies of abdominal wall	1
759.9: Congenital anomaly, unspecified	1

**Table B-2. (Continued)**

Disability Descriptors	Inferred Eligibility Codes <sup>a</sup>
Group_R: Prenatal/Perinatal Factors	
ALG R: Prenatal/Perinatal Factors	
362.21: Retinopathy of prematurity, ROP	1
760.7: Prenatal substance exposure	1
760.75: Prenatal cocaine/crack exposure	1
760.79: Prenatal exposure, other	1
761.5: Multiple pregnancy	1
763.9: Unspec labor/birth complication	1
764.9: Fetal growth retardation	1
765: Prematurity, low birth weight	1
767: Subdural and cerebral hemorrhage	1
767.6: Brachial plexus injury	1
769: Hyaline membrane disorder, RDS	1
770.1: Meconium aspiration	1
770.6:Wet lung	1
770.8: Other respiratory prob after birth	1
771.1: Congenital cytomegalovirus	1
772.1: Intraventricular hemorrhage, IVH	1
778.6:Hydrocele	1
779: Convulsions in newborn	1
779.5: Newborn drug withdrawal syndrome	1
779.8: Abnormal muscle tone	1
783.3: Feeding/sucking problems	1
Group_S: Infections	
ALG S: Infections	
382.9: Otitis media	1
Group_T: Other Illness/Injury	
ALG T: Other Illness/Injury	
851: Brain damage, brain injury	1
Group_U: Chronic Diseases/Neoplasms	
ALG U: Chronic Diseases/Neoplasms	
191: Malignant neoplasm of the brain	1
277.5: Hurler's syndrome	1
s40230: Lung disease	1
Group_V: Musculoskeletal Disorders	
ALG V: Musculoskeletal Disorders	
550.9: Bilateral inguinal hernia	1
729.1: Congen generalized fibromyotosis	1
754.1: Torticollis	1
754.5: Varus deformities of feet	1
756: Anomalies of skull and face bones	1
756.9: Oth and unspec musculoskeletal	1

**Table B-2. (Concluded)**

Disability Descriptors	Inferred Eligibility Codes <sup>a</sup>
Group_W: Central Nervous System Disorders	
ALG W: Central Nervous System Disorders	
335: Anterior Horn Cell Disease	1
342.9: Hemiparesis, hemiplegia	1
343.9: Cerebral palsy	1
348.9: PVL, periventricular leukomalacia	1
741.9: Spina bifida w/o mention hydrocephalus	1
742.1: Microcephalus	1
742.3: Hydrocephalus	1
742.4: Other specified brain anomalies	1
Group_X: Other Specified	
ALG Xa: Other: Hospital/medical treatment	
Xa: Other: Hospital/medical treatment	1
i409: Respiratory problem, ventilation	1
Group_Y: Physical Environment	
ALG Y: Physical Environment	
Y: Physical Environment	2
ALG Ya: Physical Envir: Product/obj/mat'l	
V44: Tracheostomy, trachtube placement	1
V44.1: Gastrostomy, g-tube	1
Group_Z: Social Environment	
ALG Za: Social Environ: Family/caregivers	
Za: Social Environ: Family/caregivers	1
995.5: Child neglect/abuse, unspecified	1
V61.29: Foster care, adopted child	1
V61.8: Parent/sib mental/behav/disability	1
Group_BB: Commual Infrastructure/Environ	
ALG BBa: Commual Environ: Education	
BBa: Commual Environ: Education	1